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# "You Have to Have Tough Skin": The Impact of Social Exclusion on Immigrant Mothers of Children with Disabilities

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“YOU HAVE TO HAVE TOUGH SKIN”  
THE IMPACT OF SOCIAL EXCLUSION ON  
IMMIGRANT MOTHERS OF CHILDREN WITH DISABILITIES

by

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A Major Research Paper  
Presented to Ryerson University

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Master of Arts  
in the Program of  
Immigration and Settlement Studies

Toronto, Ontario, Canada, 2008

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“YOU HAVE TO HAVE TOUGH SKIN”

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Master of Arts

Immigration and Settlement Studies

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ABSTRACT

This exploratory research considers the way gender, racialized ethnicity, and disability, as markers of difference, contribute to the social exclusion experienced by immigrant mothers as primary caregivers of child(ren) with a disability. Interviews were held with eight immigrant mothers in the Greater Toronto Area exploring barriers to accessing informal, formal networks of support, and the resulting impact on their lives. The findings include a lack of ethno-specific and extended family support as well as a lack of accessible, transparent government, social service information, and service provision. Other issues concern language, equity and access to services, impact on personal health, caregiving for aging parents, and future concerns for their children’s short and long-term welfare. Recommendations are based on a social inclusion framework of principles, which are relevant to policy makers, service providers, educators, and members of society.

Key Words:

Immigrant mothers; caregivers, children; disability; social inclusion/exclusion.

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I would like to thank many individuals for their interest and support during this project including my family, friends, and supervisor, Professor Melanie Panitch.

I dedicate this project to all of the women who participated in this study. I wish for them continued courage, strength, energy and laughter. May their day-to-day realities continue to inspire change at a personal and societal level.

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*We were not English speaking...there were many problems and ups and downs... my relationship with my husband... the big transition between my country, Canada, and the new language... plus the persecution trauma that we had. It was everything at once...It was amazingly overwhelming when...I got the diagnosis...you have to have tough skin.*

Mothers have always played a vital role in their children's lives for they are often the glue holding families together regardless of the complexities of intra-familial relationships, the instability of political or economic regimes in their countries, or the processes of immigration and settlement in Canada. As a result of both teaching and travel opportunities in various parts of the world, including Canada, an intense curiosity developed in me as a result of working with children with various disabilities and their mothers. My travel experiences gave a privileged glimpse into some of the day-to-day realities, which both children with disabilities and their mothers had to endure in their home country. These experiences illuminated my understanding of the various political, socio-economic, and personal challenges, which mothers face and provided a partial, but essential social and cultural context for this paper. Immigrant mothers who have immigrated to Canada have had to work through layers of complex pre-migration and long-term settlement issues. The challenges, which certain immigrant mothers face as newcomers to Canada, are formidable; challenges that society often overlooks. A small body of literature supports this understanding indicating that immigrant families, particularly the mothers, experience many difficulties as they immigrate, settle, adapt to a new environment, learn a new language, negotiate new cultural norms, and provide for a child with special needs (Lai & Isha Ishiyama, 2004; Stewart, et al., 2006; Sandys, 1998).

Families also experience migration and settlement differently and over different lengths of time. Some family members might immigrate with family, while others might arrive alone. Some might have language skills and perhaps existing informal networks of support from their ethno-specific community in the Greater Toronto Area (GTA). How these levels of informal ethno-community supports are sustained to support families and particularly mothers when they have a child with a disability has been under researched in Canada. Furthermore, depending on the type of disability and levels of informal or formal

supports, which mothers receive, mothers' challenges may not necessarily be confined to the short-term; on the contrary, they may continue indefinitely and last well into the second generation (Omidvar & Richmond, 2003). This result raises a number of issues and pertinent questions: How are immigrant women supported in their caregiving and what are the challenges that they face in obtaining the supports they need to support their children? How do these challenges lead to social exclusion?

Specifically, this paper explores the role of a mother as a primary caregiver and the ways in which she negotiates markers of difference such as gender and racialized ethnicity. Since her child's disability impacts her life, the study will further examine the mother's experiences related to the types of barriers that exist in accessing formal and informal levels of support. As mothers immigrate and settle, their day-to-day experiences can lead to social exclusion if the care, which they provide to their children with disabilities, remains invisible and goes unrecognized by the government and society.

Focusing research on immigrant mothers is an important field of study since these mothers are prone to social exclusion based on their gender and their ethnicity, which compounds receiving minimal informal or formal supports when they have a child with a disability. Socialist feminist thought would also support this area of study as it concerns government support of both mothers and families. Arat-Koc (2006 b) agrees that in a broader sense of caregiving, "child care should not be a private responsibility of the mother or of the family, but that society and the state should at least share in the work, cost, and responsibility of raising children" (p. 86). In particular, this includes supporting immigrant mothers with children with disabilities as stated in the proverbial, "it takes a village to raise a child." Community Living Ontario offers a different slant emphasizing social inclusion of the child, but also of the family and community through its social community inclusion initiative, "It Takes a Village, Where All People Belong" (Community Inclusion Project, 2007).

Irrespective of marital status, age, culture, language, or socio-economic status, all mothers' experiences are valuable and their individual experiences unique amidst the shifting boundaries defining the traditional nuclear family. However, this does not dismiss an immigrant father's important caregiving

role in family life, his relationships surrounding parenting a child with a disability, intra-familial relationships, and employment. Although not a focus of this paper, the father's experience is important to acknowledge, as it raises other important questions about gender, particularly the needs of fathers as they negotiate immigration and settlement in Canada.

I held interviews with eight immigrant mothers whose unique situations provided rich details for the purpose of this paper, which brings together gender, racialized ethnicity, and disability. The combination of these elements demonstrates the mothers' vulnerabilities as well as their incredible strength, resilience in overcoming challenges, and their incredible passion for life. As the researcher, it is my hope to pass on their heart's desire in creating change at an institutional and societal level for both themselves and their children. The paper begins with an explanation of key concepts, a review of the literature, a description of the methodology followed by the findings, and a discussion based on interviews. Other points the paper addresses are the benefits, limitations, and key recommendations addressing policy makers and service providers. "Looking Forward" will address areas for future research, which will be followed by the conclusion.

### Key Terms and Concepts

To understand the relationship between key concepts, it is necessary to identify them and the way in which they will be used in this paper since some concepts, Burstein and Duncan (2003) both agree, can be highly politicized and in constant "terminological flux"(p. 458). Second, the need for an intersectional approach recognizes that the categories of gender, racialized ethnicity, and disability, when studied on their own produce a singular category and very limited perspective. Combining these variables offers a deeper qualitative intersectional analysis of the complexities facing immigrant women by considering the sometimes overt and sometimes more subtle, multi-layered, systemic forms of exclusion that immigrant mothers face in Canada. (*Ontario Human Rights Commission An Intersectional Approach*, 2001).

Gender is a central concept when considering how immigrant women negotiate the responsibilities of caring for their children and families. Looking more closely at the work, which women undertake, in the private sphere of their homes is an important issue. Mackenzie argues (1986) that the unpaid work which women engage in “is invisible to the public sector” (p. 88). Making visible the family situations of immigrant mothers with children with disabilities is essential in understanding the invisibility of increasing domestic work in the home, and the ability for mothers to manage these responsibilities full-time. Studying women’s labour is also important because across cultures the undervaluing of unpaid women’s labour in the home “is closely linked to women’s lower power and status, for it leads to the perception that women do less work and are therefore less important to societies” (Burn, 2005, p.100). Consequently, I hope that by examining women’s under recognized caregiving work in the home, greater attention, visibility and support will be generated to help them provide for both the short, and long-term needs of their family, their children, and ultimately themselves. As Mary Chinery-Hesse, the Deputy Director General of the International Labour Organization states, “All women are working women whether they are engaged in market or non-market activities” (Burn, 2005, p. 98).

The role of mothers is often generically referred to as parents. While it is important to recognize both the combined and singular needs of parents, the mother’s role will be specifically referred to in this paper since women often assume the majority of responsibilities associated with this caregiving role (Gombay, 2003). In addition, as mothers, advocates, and the principle actors in juggling multi-tiered family responsibilities, women are often the principle family member in obtaining supports for their children with or without special needs. Immigrant women may face additional burdens in providing this care. Their situation may be compounded by the fact that they are often marginalized because of “subordinating constructions of gender and through ethnic and racial stigmatization” (Castels, 2000, p. 197). This paper will also explore the experiences of single mothers who face even greater parenting obstacles and social exclusion.

Klein (1983) states the importance of carrying out research for women and defines it as taking women’s needs, interests, and experiences into account while at the same time being instrumental in

improving their lives (as cited in Webb, 1993, section C1). Feminist research also focuses on the voices and meanings, which women make of their experiences, which are all uniquely expressed. Diversity characterizes the research, as there is not one way to conduct it. As well, feminist research addresses critical issues such as anti-racism, democratic decision-making, and the empowerment of women, particularly marginalized women (*Introduction to feminist research*, 2007, ¶1).

I distinguish the term “immigrant” from “newcomer” to differentiate between mothers who were more “recent” arrivals in comparison to other mothers who had been in Canada for more than ten years. The paper captures the mother’s short and long-term settlement experiences as seven of the eight mothers in this paper have resided in Canada for more than ten years while one mother recently came as a refugee. The sample explores a broad range of settlement experiences over time and emphasizes the importance of considering the mothers’ own reflections of her transitional and settlement experiences in the GTA.

This paper also uses immigrant to describe the mothers in this study who were both first and second-generation women and the two mothers who were refugees. It is however, not a term that will be used to homogenize or essentialize their experiences, but will be used only because there is no suitable replacement. Therefore, the reference to immigrant in this paper will be used going beyond the constructs of the word so as to look more closely at the mothers’ individual immigration experiences over time. Therefore, I hope to create a deeper awareness and new ways of appreciating the mothers’ experiences in order to inform the public conscious and effect changes in public policy.

The term racialized ethnicity is defined as: “those aspects of Canadian society that overtly and covertly attribute value and normality to White people and Whiteness and that devalue, stereotype and label racialized communities as “other”, different, less than or render them invisible” (Lopes & Thomas, 2006, p. 270). The authors add that this can exist at an individual, institutional, and systemic level (p. 270). As a by-product of racism, discrimination is defined as “the unequal treatment and differential allocation of resources to individuals who are members of particular social groups.” Discrimination may be based “on race, nationality, sex, gender identity, age, religion, political affiliation, marital or family status, physical or

psychiatric disability, sexual orientation, or class” (p. 266). Racialized ethnicity also has a historical component that the Literature Review will address.

I refer to “race” as “racialized ethnicity” or racialized person as it is expressed by Lopes and Thomas (2006) who state that “race is a social construct rather than a description of perceived biological traits” (Lopes & Thomas, 2006, p. 270). Li (2003) refers to racialization as “the process by which society attributes social significance to groups on superficial physical grounds” (as cited in Smith, 2003, p. 112). More specifically, Todorov (2000) elaborates on the meaning of racism as behaviour, the manifestation of contempt and ideology and “the doctrine concerning human races” (as cited in Smith, 2003, p. 114). I will look into the ways that racism figures into the disability and immigration discourse and the way it might be consciously or unconsciously recognized. This could also include that which is not visible since language and accent, coupled with differing types of disability, figure largely into this intersection and create a fertile ground for discussion.

Racialized ethnicity is not a new term, but one that will hopefully help to facilitate larger discussion in the way it intersects with disability in the day-to-day lives of both first generation immigrants and the generations to follow in the GTA. Increasing immigration to the GTA means that by 2017 “one in five Canadians will be ‘visible minorities’ and will constitute more than half the population of Toronto and Vancouver” (Lopes & Thomas, 2006, p. 270). It is therefore vital to encourage further support and create additional services, which facilitate both the short-term and more importantly, the longer-term settlement experiences of immigrant families, particularly if a family member has a disability.

“Disability” is a malleable term and refers to a range of human differences such as age, health, physical and mental abilities and economic status (Gleeson, 1999, p. 6). One’s environment is a key factor. Oliver (1990), a key theorist in the field of disability studies, refers to disability as “the social experiences of people with some form of physical impairment to a limb, organism, or mechanism of the body” (as cited in Gleeson, 1999, p. 6). Gleeson (1999) believes that this could be organic in nature and could manifest itself as a physical or intellectual impairment (p. 6). On the other hand, Barnes (1996) states that

“impairment is not something which is peculiar to a small section of the population; it is fundamental to the human experience whereas, disability...is not; like racism, sexism, heterosexism, and all other forms of social oppression, it is a human creation” (as cited in Gleeson, 1999, p.26). Disabled People’s International distinguishes between the two terms “impairment is the functional limitation within the individual caused by physical, mental, or sensory impairment. Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers” (www.dpi.org).

It is important to outline the two approaches to understand disability including both the medical and social models. Both are fundamental to disability studies, and cannot be studied in isolation. The medical model focuses on impairment as the root cause of a person’s problems with a focus on one’s physical limitations; individuals are often “defined” and “labeled” by their disability, for example, “disabled person” instead of “person with a disability.” Consequently, medical professionals, communities, and to some extent the public at large view individuals with disabilities as lifelong patients who are in need of treatment” (Jones, 2003, p. 13). A top-down approach gives individuals with disabilities, and their families, very little opportunity to influence the growth of services that they need.

On the other hand, the social model of disability views disability “in the way society is organized and takes, or does not take their needs into account” (Tregaskis, 2004, p. 12). It adopts a people first approach where the disability is secondary to one’s identity and does not define an individual against benchmarks of normalcy. Zola (1989) adds that disability is a “universal human experience” (as cited in Shakespeare, 2006, p. 203) and one that is both borderless and colourless.

Given that impairment affects all individuals at some point in their lives, I will refer to “impairment” in this paper in its broader sense as a “disability.” This will take into account the social aspect of the disability, its relationship to families, and the wider social spectrum. Although the social model has been recognized as not fully addressing all elements of social inclusion, Oliver, one of the fathers of the social model, states that it was a “starting point for discussion of the issues” (Tregaskis, 2004,

p.12). Consequently, other elements of the social model are becoming more apparent and include other social divisions such as race, gender, and aging.

With an increasing aging baby boomer population, in relation to other generations in Canada, Foot states that the social significance of the size, characteristics and behaviour of the baby boomer population “will dictate most major consumer trends, including patterns of education enrollment and health care utilization, with the costs associated with the latter expected to skyrocket” (as cited in Wister, 2005, p. 199).

These trends raises questions about disability service provision in the Canadian context, but particularly in a provincial and municipal context. Amidst the tension between cutbacks and the need to create greater numbers of disability services to accommodate “disability” in general comes the situation of balancing this provision for the special needs of children, adults, and aging individuals. How are the very different needs going to be addressed, supported, and sustained in the future? A similar parallel identifies increased immigration as adding other settlement layers to the question of disability service provision. According to recent Statistic’s Canada immigration figures, Canada is now home to its highest number of immigrants since 1931 with increased settlement in Toronto between 2001 and 2006 (Reinhart, 2007, ¶1). If the demand on services is potentially going to increase, then service provision in the disability and settlement sector needs to be strengthened. Both issues affect the social inclusion of immigrants.

The degree to which a child has a disability impacts the lives of children, mothers, and families in very different ways. In this paper, while some of the children had mild disabilities (mild autism, or learning delays), other children experienced more severe disabilities which included medical and/or behavioural issues, requiring very separate levels of parental and medical intervention. All of the children’s disabilities were biologically acquired, thus differentiating them from children who may have acquired a disability later in life as a result of an accident or developmental disability surfacing at a later point in time. For the purposes of this study, the terms, “children with a disability” or “special needs”, will be broadly used to refer to a range of disabilities as opposed to a “type” of disability.

## II LITERATURE REVIEW

The literature review will be comprised of the following: a) theoretical framework, b) historical immigration perspective and policy, c) settlement issues, and d) supports and resources.

### Theoretical Framework

This paper grounds itself in a social inclusion framework incorporating principles of access and equity. It frames the concept of social inclusion within the lived experiences of immigrant mothers experiencing settlement and will illustrate the realities of growing social exclusion for new immigrants. This growth will be explored by showing how sociological, cultural, and economic systems are inaccessible and inequitable for some, but can be remedied if resources are provided to resolve systemic barriers of discrimination (Omidvar & Richmond, 2003). The investigation will look at discrimination from an anti-racist perspective addressing Canada's immigration discourse that is deeply influenced and shaped by long standing political, ideological, and historical perspectives established by British imperialist "norms" and an established "status quo" contributing to a consequential "othering." This is realized in an "us" and "them" mentality marginalizing many immigrants (Li, 2003, p. 3). It also prevents their full integration as a result of an "unequal relationship between old timers and newcomers, and the power and influence of the former to set terms and expectations under which newcomers are expected to change" (p. 11).

Although Canada's multi-cultural policies respect cultural differences and diversity, Li (2003) further states that its commitment to diversity is highly debatable. He points to the use of the terms "contributing members of society," "adjustments" and ability to "adapt" to illustrate his point (p. 4). This is demonstrated in the language of integration discourse where Employment and Immigration Canada (1993) states: "Immigrants who are successfully integrated into all aspects of Canadian life should compare favourable with other Canadians in measurable aspects of social and economic life" (as cited in Li, 2003, p. 4). According to Li, Canada determines notions of "successful" integration with a top-down approach indicating "the importance of shared values and compliance to the Canadian standard of life as essential to

successful integration” (p. 4). Integration merges closely with social inclusion since belonging and acceptance are fundamental to the lives of newcomers. However, “the warmth of the welcome” (Reitz, 1998), may not be so fully extended should ‘differences’ and attitudes towards specific ethnicities and disability ‘colour’ perspectives and understandings of how immigrants should integrate, as opposed to how Canada can more readily facilitate their integration, belonging and inclusion into everyday life.

According to Li (2003), social inclusion “extends beyond bringing the ‘outsiders’ in, or notions of the periphery versus the centre. It is about closing physical, social, and economical distances separating people rather than only about eliminating boundaries or barriers between *us* and *them*” (p. 3). Consequently, employing a social inclusion framework in this paper will be particularly relevant because immigrant mothers often face exclusion and marginalization on a number of levels: as women and mothers, as immigrants, and as mothers of children with disabilities. I will elaborate on ways to circumvent exclusion in the next section.

Using Omidvar and Richmond (2003) social inclusion framework, the authors cite five elements of social inclusion that can be directly applied to policies preventing the increasing marginalization of immigrants (p. 14). These core foundations will:

1. address a life cycle approach that pertains to long-term settlement needs;
2. address the economic, social, and political exclusion of large numbers of immigrants who are settling;
3. mobilize all relevant actors in a joint effort involving “federal, provincial and municipal governments in tackling the challenges of newcomer settlement and incorporate all stakeholders in a policy response including settlement agencies, mainstream institutions, employers and private foundations;”
4. develop and implement anti-racist policies particularly those from a visible minority;
5. ensure that evidenced based policies speak to the need to increase practical and transparent measures of public accountability. This would increase immigrant and refugee’s participation in the “economic, social, political and cultural life of their new homeland

Coupled with settlement, disability will be discussed as part of critical and under-looked factor of social inclusion as experienced in the daily-lived experiences of immigrant mothers. Existing literature on social inclusion by Chard et al., (2000); James et al., (1999); Mohab 1999; Preston and Man 1999 identifies gender as playing an important role since the experience of immigrants and refugees (as cited in Omidvar & Richmond, 2003, p. 5) is often gendered. This perspective provides an understanding of the multiple dimensions of economic and social exclusion for immigrants (p.5) the roots of which are grounded in early historical immigration policies that will be discussed in the next section.

### Historical Immigration Perspectives

A difficulty in addressing racism in Canada relates to a poor and lamentable understanding of Canada's history and a consciousness about its past and present "race" relations (Smith, 2005, p. 21). Consequently, it is important to consider the policies that have shaped the present day Canadian consciousness. This consideration involves the formation of a nuanced understanding of immigration as it relates to gender, racialized ethnicity, and disability and social exclusion. Commenting on the reading and writing of history, Arthur Schlesinger Jr. writes:

It is useful to remember that history is to the nation as memory is to the individual. As a person deprived of memory becomes disorientated and lost, not knowing where they have been or where they are going, so a nation denied a conception of the past will be disabled in dealing with its present and its future (as cited in Lapham, 2007, p. 9).

Historically, defining Canada as a nation was a prime motivation of western colonial expansionism. Canada's turn-of-the-century immigration policies were outwardly racist towards immigrants and those outside the boundaries of the British Isles and initially Scandinavian countries (Arat-Koc, 2006a, p. 203). Membership within the Dominion was racialized according to established and exclusionary norms of whiteness rendering immigrants and First Nations people socially invisible in the Canadian landscape. Canadian identity was set according to Imperialist English values and ideals of racial

superiority. The “othering” of all non-English essentialized the status and racial superiority of the white settlers, particularly white genteel English settler women, considered the “future mothers of the nation” (p. 200).

Colonial history is linked to immigration since Aboriginal women, faced not only exclusion, but also subordination in that they were compared to white English settler women. In terms of exclusion, Bhabha (1994, p. 44) explains that one’s mere existence called into being one’s “relation to an otherness, its look or locus” leading one to question “where are you from?” (as cited in Nestel, 2006, pp. 153-154). This guaranteed the emergence of a systematic use of “othering” which was racialized, gendered, and purposefully employed against Aboriginal women in particular. Fanon (1992) indicates that this primarily sealed Aboriginal women into “crushing objecthood” (as cited in Nestel, 2006, p. 154) thus leading to their immediate inferiority and subordination.

Hegemony also stereotyped Aboriginal women as a threat to the young, genteel, English settler woman’s “true womanhood” prized for their future role as mothers of the nation (Arat-Koc, 2002a, p. 201). Exclusionary frameworks were enforced by gatekeepers made up of a collective number of philanthropic organizations, individuals, church people, educators, doctors and community workers whose goal was to “engage in a sporadic, but vigorous campaign to raise the moral tone of the Canadian society and in particular urban working-class communities” (Valverde, 1991, p.17). This was realized by “policies [set] in motion...segregating the ‘new’ community from indigenous contacts (Carter, 1996, p. 30). As a result, Aboriginal women (and men) were systematically marginalized and physically segregated to a life on reserves.

The same fears held true for newly arriving immigrants, whose “foreign” ways were considered different, and displaced from the norm. Settler women had limited contact with some immigrants (and Aboriginals) who were considered strangers, perceived threats and were marginalized as well. The official “gatekeepers” cautiously monitored immigrants determining who got in and who was allowed to stay (Iacovetta, 2006, xii). Only individuals considered “productive” would be allowed to stay since individuals

considered to be a 'burden' would not integrate into society and thereby hamper political, economic and social progress. Such stringent rules were established at the onset of the development of the Canadian West and continue to reappear in Canadian immigration policy (Carter, 1996, p.17; Troper, 2003, p.24).

Notions of 'productivity' framed Canadian immigration policy and the current point system that values an immigrant's 'abilities' and skill sets that contribute to the wider good. However, what is not readily discussed today is the application of such Canadian immigration policies towards immigrants or refugees with a disability and how physical versus unseen disabilities figure into policy determination. Although current immigration policies will not be discussed in detail in this study, related issues do need to be raised since Canadian immigration laws are founded on social principles grounded in political, social and historical power and they do have an exclusionary effect prizing certain individuals over others.

Antonio Gramsci, the famous proponent of the theory of hegemony, best demonstrated such power stating that: "ruling elites dominate society not solely by the threat of coercive force but by shaping popular consent" (Iacovetta, 2006, p. 58). Political and social beliefs also influenced popular attitudes towards immigrants. This was usually illustrated by way of scare tactics such as "the yellow peril" where fear was instilled as a way of maintaining boundaries, particularly against the "mixing of races" (Valverde, 1991, p. 32). Kelley and Trebilcock (2000) note how exclusionary sentiments persisted and influenced public opinion. At a political level, Prime Minister Mackenzie King stated that the mixing of the races would bring "Canadians face to face at once with the loss of that homogeneity which ought to characterize the people of this country if we are to be a great nation" (p. 203). This was echoed by the president of the Trades Labour Congress, Percy Bengough, who in 1946 reinforced these sentiments stating, "there are citizens of other countries who may be good brothers and sisters, internationally, but ... would not be accepted as brothers and sisters-in-law to Canadians" (p. 316). Rousing such insecurities and fear reinforced differences and exclusionary policies.

In sum, the hegemonic creation of difference was deemed necessary to establish a class system and boundaries of 'privilege' for only a few. Strains of difference permeated structural systems had long

standing effects in Canada and impacted immigration policy in the years following the turn of the century. An example of this is found in early twentieth century eugenics theories which impacted the selection of certain immigrants who were deemed incapable of fitting into the harsh climate of the north as they were considered to be lazy and unmotivated “and who in winter generally shifted to a warmer latitude in the Unites States” (p. 83). In addition deterrents were set up to discourage certain immigrants from believing that they could establish themselves in Canada since “only the strong could endure its rigours, giving rise to an energetic, self-reliant, healthy race” (p. 81).

Eugenics beliefs on population control were also considered the solution to the ills of high urbanization from immigrants outside of northern European boundaries as increased poverty, crime, unemployment, diseased, and degeneracy were attributed to high numbers of alcoholics, criminals, prostitutes who were considered to be suffering from feeble-mindedness and therefore rendered unsuitable for settlement (p. 213). Immigrants from the hardy stock of northern European countries were praised based on principles of Aryan beliefs of racial superiority and quality. In 1902, Clifford Sifton promoted immigration from Central, Eastern, and Northern European countries by providing financial incentives to trading companies and booking agents for securing immigrants from these aforementioned “preferred” areas of Europe (p. 120). Such ideas were prevalent at the turn-of-the-century and contributed to eugenicist ideas, which impacted subsequent immigration selection policies.

Immigrants continued to be subject to strict selection policies. This criterion was again based on their “suitability,” and capacity to contribute both structurally and economically towards nation building initiatives. However, strict measures were set in place to ensure that newcomers were abled-bodied and not an “excessive burden” on the community. Criteria was often racialized and “a well-defined pecking order of prejudice” ensued where “race proud Anglo-Saxons ...were prejudiced against everybody else” (Kelley & Trebilcock, 1998, p. 221). Deportations were frequent should non-conformity or the lack of one’s ability “to establish” one’s self in Canada challenge the status-quo (p. 192). Disabilities figured prominently into deportation policies lest impairments counter forward moving nation building strategies; at one point, varicose veins and foot trouble were grounds for deportation and also included settler women

“who transgressed moral conventions” (p. 192) Other offences included feeble-mindedness, moral misconduct, crime, and laziness (p. 192).

Although Canada is a nation constructed and built by immigrants, traces of ‘ablest’ and racialized notions figured prominently in the discourse of the country’s immigration policy. These frameworks led to the justification of “policies already in motion” (Carter, 1996, p. 30) segregating longer term Canadian-born (i.e. further than second-generation born) and newcomer immigrants. Immigration policy strategies streamlined immigrants according to scripts of preferred qualities. Although immigrants were needed for economic reasons, they were racialized and consequently treated as second-class citizens throughout their settlement period.

Racialized women with disabilities have faced social and political exclusion in Canada. If a disability was acquired in Canada, they were often shunned, or deported. Attempts were (and to some degree still are) made to keep individuals with a disability, particularly women who are “marked as different...[and rendered] socially invisible, by keep-them-out immigration policy” (Dossa, 2006 p. 352). It can be argued that today, immigrant mothers with children with disabilities face similar situations in immigrating to Canada raising further issues about immigration policies. For those who have immigrated with a child with a disability, or may have had their child here in Canada, both the mothers and their children may face other social challenges in Canada, which are similar to women who have disabilities. In the case of women with disabilities, Dossa (2006) states that their concerns have been ignored by social services, “and if they are identified, every attempt is made to keep them in the private sphere through such strategies as making services inaccessible and withholding information that would improve their quality of life” (p. 352). In addition, Dossa further adds that the political dimension also:

denies the rights and privileges of individuals with disabilities that are extended to white/mainstream persons with disabilities...[and]...this explains why disability organizations and advocacy groups do not substantively address concerns and aspirations of racialized women and men with disabilities. (p. 352)

Race is a necessary factor to consider in the disability and settlement discourse since awareness and discussion could alleviate societal colour blindness and further prejudice. This will be further discussed in the Findings.

Internationally Canada is considered as a tolerant, compassionate, and humanitarian immigrant receiving country and one that is accepting of new immigrants (and refugees). While this is true, consider that Canadians do not hide behind an understanding of itself as a “polite and tolerant society” (Smith, 2003, p. 121). This is an important area to address because white people who are or might be aware of racial oppression, may seem to be less aware of race privilege considering it as “external to them and not as elements that shape them and their reality” (Dua, 2000, p. 31). It may also be consequentially manifested in that which Jacobs terms as “race manners,” the “fear of frankness,” or Canadian politeness as it is also known (Smith, 2005, p. 123). Stating it in this manner is one way towards creating recognition, awareness and the implementation of institutional and societal change, which is the first step in the long road ahead towards social inclusion for immigrants with a disability and their families.

The next section of the literature review will review some important settlement concepts affecting immigrants, particularly immigrant mothers. While negotiating a disability poses many challenges, additional immigration and settlement factors inform the experiences of immigrant women and are key areas to understand if support is to be effectively directed towards their needs.

### Settlement Issues

The “push and pull” factors to come to Canada are numerous (Kelley & Trebilcock, 1998, p. 45). Immigrant mothers may leave their home country due to political and/or economic instability. Others emigrate to join family who may have immigrated at an earlier time. Regardless of their reasons for emigrating, immigrant mothers desire a better life for themselves and their families. Newcomers arrive with the expectation that they will be able to pursue this better life, but may not always be aware of settlement

ebbs and flows, or turbulence that may persist over time. Although Canada has come a long way in the past fifty years in facilitating settlement services for immigrants, settlement is experienced differently by each individual depending on the services which immigrants are able to access and avail of over the short and long-term.

After mothers immigrate, they experience many acculturation challenges during settlement, which are further intensified by the “multiple jeopardy” of negotiating language, cultural norms, health, social programs, and services as they adapt to a new life in Canada (Lai & Ishu Ishiyama, 2004, p. 4). The level of navigation is different for each mother. Some mothers are equipped with computer and English language skills, for other immigrants, this might not be the case. In the latter, illiteracy and language, issues are the main barriers to accessing the support systems that some mothers need, whereas, for others, it is the lack of transparency of services, of knowing-where-to-go, which creates barriers to obtaining this support. In addition, Noh and Kaspar (2003) note that since many immigrants find themselves “functionally illiterate” in navigating the social and medical service sectors, they are also the least likely to receive cooperation from physicians and health-care workers (p. 352).

Their situation may be compounded by the lack of ability to access telephone or web based information, also known as the “digital divide” as well as a professional’s understanding of how they accessed and understand the information which they acquired (Caidi & Allard, 2005, p. 5). Breaking these barriers would help to build “social capital” which the OECD (2001) report defines as “networks together with shared norms, values and understanding which facilitates cooperation within or among groups (as cited in Caidi & Allard, 2005, p. 3). Both Caidi and Allard argue that “social inclusion/exclusion can be thought of as an informational problem that has to do with access (or lack thereof) to meaningful and relevant information that fulfills the needs of immigrants” (p. 5). This is an important area for discussion and is relative to many immigrant families and mothers who may be socially excluded from essential services, which for the most part, may be primarily based on this lack of information.

Navigating the system and knowing where to go for help is not an easy feat as indicated by Chatman's theory (1985) of "information poverty" which describes an individual's difficulty or inability to obtain useful information from people they know (insiders), outsiders to their group, or even from the mainstream sources of information such as the media (as cited in Caidi & Allard, 2005 p.3). Such challenges may prevent immigrants from accessing vital information services (p.3). An illustration of this is best demonstrated by one web based service provider who replied to a newcomer's medical finance query stating, "I did some looking around, but it was hard to figure out where to get started" (Montague, 2007).

Such a comment attests to the fact that although immigrants face increased settlement challenges, they are not isolated in their attempts to navigate complex systems as service providers may have difficulty navigating the service maze, and may therefore be considered "information poor." In addition, service providers may lack vital information addressing practical, cultural, social, and economical information about ethno-specific communities and the long-term supports that are required to assist immigrants in their day-to-day and long-term functioning. An example of this could be a service provider's "culturally constructed" (Wilgosh, Sobsey & Scorgie, 2003, p.200) view of family based on the impression that an individual with family and perhaps extended family networks in the GTA might automatically receive support from their family. This reality might not necessarily be the case since families, which might appear to be thriving, may actually in fact be crumbling (p. 203). As a result, mothers may be overlooked or isolated particularly if the immediate or extended family or community negatively perceives the disability.

Bowers (1984) notes that "cultural capital...the knowledge and skills with which we negotiate our way in society as competent adults" (as cited in Kalyanpur & Harry, 2004, p. 532) is an issue of concern pertaining to "information gaps" between immigrants and service providers. Caidi and Allard (2005) state that "more research is needed that shows how the attributes of the social networks affect immigrants' ability to find information, resolve problems, or to deal with situations in their everyday lives" (p.3). In addition, they also note the importance of the need for professionals to exercise sensitivity concerning how immigrants acquire their information and what sense they are able to make of it (p.3). Understanding this information contributes to a reciprocal understanding of cultural key points which contribute crucial

building blocks towards building cultural and social capital, thereby contributing to an immigrant's overall social inclusion.

There is a wide body of literature on mothers of children with disability, however little academic literature addresses the issues relating to immigrant parents and mothers of children with disabilities in Canada. What does exist, concentrates on primarily Asian communities in Canada. Some of the following examples of academic literature will illustrate the experiences of parents and mothers with a child with special needs. For future research, qualitative ethnographies would be beneficial as they would give specific, pertinent cross-cultural references for social services and policy makers, and would build on studies such as Mak, Ho and Law, who found that across various cultures, parents of children with varying disabilities often experience high levels of stress (as cited in Cook P, Cook M, Tran & Tu, 1997).

Women often assume the primary caregiving role as nurturer, mediator of appointments, navigator of information systems, juggler of competing family's domestic needs as well as the extra demands of caring for a child with a disability (Porter & McKenzie, 2000, p. 67). The multiplicity of these responsibilities can have direct implications on mothers causing stress, guilt, and anxiety, particularly if mothers feel that they are "failing to 'live up to' one's notion of being an 'ideal parent'" (Burton, Lethbridge, & Phipps., 2006, p.5). Mothers can feel particularly isolated in their experiences if they are not supported in their caregiving. The authors also note the inseparability of the constructions of good parenting and the desire for their child to have a happy or "normal" childhood leading many parents to extraordinary efforts in time and money at home, at school or extra-curricular in order to provide for their child's well being (Burton et al., 2006, p. 6; Porter & McKenzie, 2000, p.67). I will not explore further the more complex related issues of good mothering literature. They are important aspects to consider as they are influenced by culture and in some cases religion. They can also have a bearing on the mother's self-esteem, her health, overall state of emotional well-being, and thus affect her ability to manage the daily complexities of caregiving.

An exploratory study by Sandys (1998) looked at key issues affecting ethno-racial individuals with disabilities in Canada. The study did not refer to the experiences of parents who have children with disabilities, but rather, adults with a disability who found the immigration system to be a dehumanizing experience. The study pointed out that immigrant adults with a disability had difficulty accessing social services and individuals blamed the service providers' lack of knowledge about the availability of diverse disability services. In addition, the participants in that study experienced discrimination in obtaining work and also faced cultural barriers.

Another Canadian study by Neufeld, Harrison, Stewart, Hughes, and Spitzer (2002) interviewed Chinese and South Asian women and found that all experienced barriers to formal supports in accessing community services for support in their role as caregivers. Some of the women cited personal resources and strategies that helped them overcome difficulties as well as family and friends who were the greatest sources of support. A connection to one community resource helped them to outreach to other services. Their findings contribute to an understanding in the way in which immigration impacts immigrant women caregivers access community resources and various social networks.

Again, in another pertinent Canadian study, Stewart et al. (2006) noted that immigrant women caregivers state that language, immigration, and separation from family compounded their caregiving experiences here in Canada. They stressed that language, time, transportation, wait lists, need for respite, and adequate day services were necessary to consider when looking at the day-to-day functioning of their lives. Recommendations included the need for culturally sensitive services.

Another, but different study also conducted by Neufeld, Harrison, Hughes, Spitzer and Stewart (2001) examined the "Participation of Immigrant Women Family Caregivers in Qualitative Research." One of the largest problems, which they address is finding culturally sensitive ways and methods of recruiting and engaging diverse groups of women in qualitative research. In their study, the authors note that finding immigrant women is a lengthy and difficult process. This is another important area to study and will be elaborated upon in the section on Methodology and on the recruitment of women.

A more recent study conducted by Corson, Ali, Frankel and Moher (forthcoming) will address the issues concerning children and families living in disadvantage circumstances. As one component, immigrant families with children with disabilities will factor into the research. Overall, these few academic studies demonstrate that although some immigrant caregiver literature exists, there are many research gaps and therefore, room for further research and discussion.

In Canada, little exists in terms of literature written by immigrant mothers about their experiences. However, one recent book deserves mention for its narrative insights pertaining to immigrants and disability: *Politics and Poetics of Migration: Narratives of Iranian Women from the Diaspora*. The author, Dossa (2004) cites one narrative, where the protagonist, Fatima a mother of a daughter with a disability, battles against numerous fronts including discrimination and social exclusion. Dossa (2004) notes that women of colour find such discrimination even more difficult and consequently struggle, as in the case of Fatima, “to have her role as a caregiver/a woman/a mother valorized and legitimated by society” (p.37). Dossa (2004) fully supports the need to have women’s stories heard if “we want to write a different kind of Canadian history, one in which women from different cultural and linguistic backgrounds have an active presence” (p.37). As a result, involving families from diverse ethnic groups, and engaging immigrant mothers to write their own personal experiences would help to broaden female perspectives and those related to disability as reflected in the social model of disability. Such literature would make an important contribution to identity, citizenship, disability, and women’s literature.

Dossa’s example supports the need for additional literature to be created and also developed by immigrant women. Neufeld’s study on the “Participation of Immigrant Women Family Caregivers in Qualitative Research” (2001), confirms this importance, but notes that finding the women and involving them in qualitative research or other such projects can be problematic. Strategies need to be constantly developed finding culturally sensitive ways to engage women from diverse ethnic backgrounds in research who may not participate due to cultural reasons, or simply the lack of time (Neufeld et al., 2001, pp.578-

579). However, as the authors note, ‘finding’ ways to engage the women in reflective projects (if they have the time!) is key to understanding the lived experiences of women.

In terms of media awareness and disability, Sherr Klein (2006) notes that few Canadian films exist regarding women and disability. To counter this reality, her film, *Shameless, the Art of Disability* (Sherr Klein, 2006) portrays the experiences of women with disabilities and their ability to continue to exercise their creative talents in very individual and unique ways. As one example in this recent film production, Catherine Frazee, a Canadian activist for persons with disabilities argues against notions of representation and normalcy that limit her abilities. She is mobile as a result of her wheel chair, but notes that “this wheelchair does not define me, [it] does not contain me” (Sherr Klein, 2006). Frazee advocates for change in social consciousness and societal environments including the way in which all people with a disability are perceived, since as stated previously, no one is immune.

Following in the footsteps of this documentary, other film possibilities could result in the day-to-day tracking of the lived experiences of immigrant women who have a disability as well as immigrant mothers who have a child with special needs. There are many possibilities to give both women and mothers a visible and vocal platform from which to talk about their lived realities and experiences with disability. These realities include their immigration experiences, settlement, family and socio-economic concerns, which are but a few examples. Such undertakings exploring these challenges would make a significant contribution to media awareness and reach out to a wider Canadian audience.

It is difficult to make general comparisons regarding immigrants’ current socio-economic status, and whether or not, immigrants are able to “get ahead” as they had in the past. Current factors implicating the socio-economic status of immigrants include the immigration class under which they immigrated (as refugees, under the family class or business class and so forth). Community and family support, gender, ethno-racial origin as well as skill-sets all contribute to socio-economic “success” Preston, Lo and Wang (2003) state that overall, “immigrants have achieved social inclusion in terms of economic rates,” but that this takes from 15-25 years to establish economic parity with those who are born in Canada (p. 254).

Consequently, persisting economic gaps may prevent immigrants from being able to catch-up economically which may have other long-term socioeconomic impacts on the family particularly if they have additional expenditures related to their child's disability and particularly if one parent is unable to work because of family responsibilities at home.

In another way, Read (2000) argues that assumptions cannot determine that an immigrant's lower socio-economic status will account for the impoverished experiences which families may have (p. 53), nor that a child with a disability will be the root cause of greater intra-familial strife and dysfunction. In fact, Hastings, Allen, McDermott and Still (2002) note that despite the many economic challenges, there may be even increased positive perceptions and family cohesion relating to the child's disability which can positively impact the family unit on various levels (p. 269). While this might be the case in some families, the economic realities of settlement are still factors to consider in acquiring economic stability.

Another settlement challenge is Canada's lack of foreign credential recognition. Immigrants coming to Canada with a professional skill sets may be forced into re-skilling. Even after so doing, employment in the new field is never guaranteed. This is a significant area for immigrant mothers who have children with disabilities; the mothers may wish to work, but the needs of their family may necessitate that they remain at home. Consequently, they may not have the time or the opportunity to re-skill, thereby forcing them to rely upon other family support or social assistance.

In the case of a family member who can work, Krauss chronicles racialized and discriminatory practices as barriers to employment in "Have Ph.D. must sweep" (2005). In this article, he notes that despite their advanced qualifications, immigrants may often be stereotyped and placed in lower paying jobs, without benefits or recognition of their skill sets. Stasilius and Bakan (2005) note that such economic and social instability spills into other areas of an immigrant's life placing them at risk of slipping into poverty, and the increased chance of only finding work along racialized lines. Recent court cases have cited discriminatory hiring practices (Jetelina, 2006) which is supported by Porter (1965) who refers to deepening, racialized social hierarchies as Canada's "vertical mosaic" (as cited in Smith, 2003, p. 121).

Teelucksingh and Galabuzi (2005) note the development of this term and state, “what was once described as an ethnic Canadian vertical mosaic, is now colour-coded” (p.2). This re-illustrates the pecking order that was mentioned earlier and the way in which immigrants continue to face discriminatory practices, social exclusion, and economic instability in Canada.

Women are also vulnerable to workplace discrimination and may not be able to access work in their field leaving them to fill service sector work or night shifts. Many immigrant mothers often abandon their skill sets and professional careers sometimes due to the lack of foreign credential recognition, or for the practical sake of managing the domestic responsibilities affiliated with caring for the multiple needs of the family as mentioned earlier. In an analysis of Canada’s Participation Action Limitation Survey [PALS] (2001), Behnia and Duclos (2003) confirm that one or the other parent may need to forgo career aspirations for the sake of the family (p. 9). Personal and critical skill building opportunities such as short-term ESL, professional development and training may not be available to mothers in the long-term. In addition, practical and cultural reasons may prevent mothers from obtaining such critical language or skill building opportunities if they lack the confidence to negotiate levels of care and long-term services needed for both themselves and their child with a special need. Due to the demands of caregiving, mothers may be too exhausted to pursue anything else particularly since the responsibility of caregiving for a child with a disability extends into adulthood affecting both the life of the child and the mother (Gombay, 2003, p.3).

Raina, O’Donnell, Rosenbaum et al. (2005) state that supporting a child with a disability does contribute to family and personal stress, which does influence parental health (*Discussion*, para. 2). According to another study conducted by Newbold (2005), many immigrants arrive in Canada with similar or better physical and mental health compared with Canadian-born, hence, the “healthy immigrant effect.” However, after ten or more years in residence in Canada, their health status begins to decline; immigrant women are more apt to report poor health at this time than Canadian-born women (Vissandjee, Desmeules, Cao, Abdool, & Kazanjian, 2004, p. 200). This idea is supported by another study conducted by Noh and Kaspar (2003) who also note the health difference between immigrants and individuals born in Canada, which the authors note, diminished substantially among immigrants who had been in Canada more than ten

years. Such a disparity is particularly significant for immigrant mothers parenting children with special needs because the mothers may be more vulnerable to socio-economic disadvantages, cultural and family stress. They may require additional community support to assist them with increased health problems, which may occur well before the ten-year period noted above.

A complimentary and more recent study supports Newbold's (2005) Healthy Immigrant Effect. It states that while there is still evidence of its existence, the effect is "not equivalent for all immigrant sub-groups, and to date, there has been little examination of the intersections within and between groups along the lines of such variables as gender, ethnicity, and length of stay" (Hyman, 2007, p.25). In essence, the author hopes that more research can focus on the overlapping and intersecting dynamics that contribute to immigrant's health needs. For this reason, considering the experiences of immigrant women who have children with special needs illustrates the added dimensions which need to be recognized in order to truly understand women's overall well being.

In terms of overall health, it is difficult to understand the complexities of women's health and emotional well-being, which is highly personal (principally as a caregiver) and may not be fully disclosed as a result of language barriers, cultural perceptions, insecurities, and so forth particularly if their child's needs are placed in the forefront. Dossa (2004) states that the mother's own perception of health and well-being may also not be fully understood by mainstream health institutions, which might refer to the mother's concerns in an off-handed manner as "issues" (p. 36). Although health will not be discussed in detail, it is an important outcome related to mother's experiences as it significantly contributes to her ability to function and to access the services, which she needs for both herself, and her family.

Parental health is also affected depending on the type of caregiving that parents provide and whether the caregiving responsibilities are shared, or if a more traditional approach is taken where the father is the breadwinner and the mother, the primary caregiver. A mother's health is also affected by the type of disability that the child has, the direct or indirect care that the parents give, and the type of regular caregiving intervention that is needed. In a study looking at the long-term parental health of parents caring

for children with chronic disabilities, mothers were cited as experiencing greater mental health problems than fathers, such as depression (Plant & Sanders 2007; Olsson & Hwang 2001). Although the former study was Australian and did not specify participation based on ethnicity, the study is relevant in that it found that the overall levels of caregiving tasks were rendered more stressful as a result of parenting a child with a disability. Burton, et. al. (2006) also examined caregiving tasks, other physical conditions, and the impact on caregiver health as a result of providing direct and on-going care.

Turnbull and Turnbull (1993) termed “cognitive coping” referring to refer to when one thinks positively or uses the way they think to alter, or manage situations (as cited in Porter & McKenzie, 2000, p. 65). This was reported to be successfully used in a study by Sandler and Mistretta (1988) who documented the use of “strategies as taking one day at a time, comparing one’s situation favourable to that of others and selectively attending to the positive factors in a situation as helpful” (as cited in Porter & McKenzie, 2000, p. 66). Although this paper will not address the deeper psychological aspects of parental coping, it does need to be recognized since these processes are essential to the day-to-day experiences of immigrants.

In a study on ethnic segregation, Qadeer (2003) points out the significant role of religion and belief systems in organizing and sustaining ethnic communities. He states that it is a major “drawing card” for families of similar faith, language base, and ethnicity. Further, he notes that in Toronto, religious connections are a “binding force” in many communities including the Jewish, Muslim, Sikh, and Orthodox Christian faiths (Qadeer, 2003). Some literature addresses the role of religion and belief systems play in families with children with disabilities (Jones, 2003, p. 31). An interesting area for further research is the role of religion role in fostering resilience and on-going spiritual support for families of various creeds and systems of belief; or the way religious beliefs, combined with cultural factors, marginalize mothers and children with disability due to shame or reasons of embarrassment. Understanding belief systems and culture is another essential element in creating a diverse and horizontal understanding of disability affecting ‘everyone’ and is a starting point from which faith groups and service providers can outreach to families.

Cultural and religious perceptions influence societal attitudes in terms of how disability is understood (Jones, 2003, p.31). These perceptions are borderless; they exist in all countries and in all mindsets around the world. Negative views of 'disability' may stem from personal experiences in the country of origin and may transfer to a Canadian context thereby influencing the way families view disability as well as the supports, which they feel they can access. The following illustrates a few different and interconnected dynamics facing immigrant families.

In Hindu culture, the laws of Karma and reincarnation are followed, disability may be seen as a personal opportunity and an obligation to care for the "special" person in this lifetime. The person with the disability may have been offended in a previous lifetime and may give other individuals the opportunity to assist them (Patil & Fisher, 1996, p. 137). In Latin America, disability may be seen as a punishment, a sin for wrong doings or it may be seen in fatalist terms, as "God's Will" (Lopez-Rangel, 1996, p.136). Lopez-Rangel (1996) states that in some parts of Latin American culture, a disability could result from a curse also known to be "mal aire" or "bad air." In addition, she notes that in some Latin American communities, respected members of the community, 'curanderos,' (traditional healers) are used to rid the evil spirits from the body by employing traditional and natural methods of healing (p. 27). Disability in Latin America may not be seen as a handicap particularly if the individual is able to work and is productive. On the other hand, a limb deficiency in this same situation may be considered a major disability and familial liability (Lopez-Rangel, 1996, p. 26).

Amongst other families, where educational pursuits are the norm, an intellectual disability (whether visible or not) could also prove to be a major stigma for families and may cause feelings of shame (Lopez-Rangel, 1996). This perception could affect a mother's desire to look for help and information relating to her child's needs. Cook P. et al. (1997) also note that in some cultures such as Asian culture, and specifically Chinese culture, children with mental difficulties were especially stigmatized and parents blamed themselves for some personal wrongdoing. In addition, they also added that the spelling of "disability" took different forms in different languages and that in Chinese characters it translates as *chan*

*fei* where *chan* means *disabled* and *fei*, *useless*. These references point to the powerful stigmatizing role that language plays in disability and in culture (1997, p.214).

Further exploration of ethnographic studies would study of this topic deserves greater attention as it pertains to ethno-specific communities in the GTA. Exploring these avenues with potential implications for social service and policy makers.

## Supports and Resources

### *Informal networks of support*

Literature on support networks indicate that immediate family is one of the most important informal support factors in assisting families (Neufeld, 2002). However, some immigrants immigrating alone, or as a single-family unit, may not have extended family, or social supports upon which they can rely making the settlement experience even more difficult.

Beckman (1991) notes that the availability of support such as family and friends, bears an important influence on the experience of parenting children with disabilities (as cited in Porter & McKenzie, 2000, p. 71). These supports are also particularly vital to immigrant families, if they are in place when immigrants arrive, and continue throughout the settlement period. Other possible informal supports, which offer a supportive role, are kinship supports, such as the role of grandparents, particularly in “dual career families” (Leung & McDonald, 2001, p. 12). What is not known however, is the extent to which immigrant grandparents in ethno-specific communities provide support to grandchildren with disabilities in the GTA, the degree to which culture plays a role and also, whether grandparents live with families or not.

Studies indicate a rise of intergenerational households in the US and UK which Fuller Thompson (2007) states is an increasing trend according to the 1996 census data in Canada, as immigrants head half of all three generational households. Cultural norms of living proximity, finances, and provision of kin

support were cited as reasons. However, no official breakdown exists in Canadian 2006 statistics (Agrell, ¶ 4).

As another informal system of support, assistance from a grandparent may be of some help to families for a number of years, but as the grandparent ages, so to does the additional caregiving role of families and especially mothers (Leung & McDonald, 2001, p.2 ). The authors recognize existing literature on women struggling to care for aging parents. However in addition to caring for children, such double parenting is a responsibility, which many immigrants may have to shoulder and may do so exclusive of any help. Wong (2000) looked at women's extended responsibilities of sustaining a home within the GTA and across national and international borders citing the impact on their social, economic, and psychological states (as cited in Aguiar, 2006, p.204). Such additional responsibilities may affect immigrant mothers in particular who may already be swaying under the weight of complex caregiving for their own children, immediate, and for some, their extended families.

As mentioned earlier, Qadeer (2003) notes the importance of religion in immigrants' lives, however, not much is not known regarding the extent to which faith communities play a role in the lives of immigrant mothers who have children with disabilities. Since culture is often tightly interconnected with faith, the acceptance of individuals with disabilities (regardless of the kind of disability) as well as the family unit may impact a family's decision to participate in community faith gatherings. Again, this is not well known and thus, another area for future research.

Studies have shown that for some parents, parental support groups can be a source of mutual support since they reduce isolation by providing parents with a place to network and share information (Porter & McKenzie, 2000, p. 104-105). However, not all support groups are helpful since some parents feel pessimistic about their child's future. Some may wish to adjust privately, at their own pace according to the age of the child and level of disability, and therefore, might not wish to socialize with other parents, which might amplify existing parental anxiety (Porter & McKenzie, 2000, p. 104-105). Immigrant

engagement or involvement in this type of informal support service is not conclusive (King & King, 2007, p.1). Language, time, socio-economic (child minding) and cultural barriers may also hinder participation

### *Formal Networks of Support*

Settlement services are still not being accessed by all immigrants; they tend to be concentrated in the City of Toronto leaving parts of the GTA including newer suburban areas under-represented and under-served in terms of available service locations (Lim, Lo, Siemiatycki & Doucet, 2005). Another component of settlement is ESL classes, which are offered to many immigrants, but are often only available in the short-term. If mothers are able to avail of classes, they might not be able to attend classes regularly or at all due to family responsibilities or because they have to work. As a result, many immigrant mothers may not acquire necessary language skills to help them access services and information. Others may be reluctant to access certain mainstream services due to language barriers and cultural reasons. The lack of foreign-trained doctors in certain communities may add to a mother's reluctance to obtain mainstream health support (Yee, 2007). This may contribute to both personal and community resource limitations. Depending on language ability and cultural proximity, women might avoid certain services particularly if the practitioner perceives disability and related issues negatively. Consequently, many immigrant mothers feel marginalized from essential services, which they need.

According to research conducted by Hayes, (1988); Nitshke (1994); Rimmerman et al. (1989) respite care is one of the most requested services for families, especially when children have behavioural, or other physically demanding difficulties (as cited in Porter & McKenzie, 2000, p. 99). However, some parents have mixed feelings about the use of respite care and may only use it when they are exhausted or in a crisis, for other parents, availing of respite care is an admission of failure (Porter & McKenzie p. 99). This feeling of inadequacy could depend on a number of factors including cultural reasons, and personal perceptions of their own role as a parent and their ability to carry out this parenting role (p.99). All of these factors would have some bearing on whether a parent uses respite care or not.

In addition, reductions of community services have pushed families into seeking alternative sources of support in the private sector such as private tutoring to private home based supports. However, these resources (such as tutoring or assistance in the home) are often unaffordable for many families including immigrant families (CCSD, 2002) and families may therefore increasingly rely upon formal community supports. These services might not be available as well due to long wait times and shortages of spaces for respite care and other essential care services.

The 1990s were marked by provincial funding cutbacks, which impacted many public service including community and social services, health care and in particular, education. School boards were not immune to funding cutbacks: programs such as ESL and Special Education were also affected. In the case of Toronto, Troper (2003) noted that educational dollars were “siphoned out of the city’s schools to support schools in the more distant suburban and rural ring” (p.60). This illuminates the demographic disparity in funding provisions for city, growing outer suburban schools, and the need for greater funding and equitable distribution as the numbers of immigrants to both Toronto and GTA jurisdictions increases.

Continued early intervention and special educational service programming such as TPAS (Toronto Partnership for Autism Services) and specifically, IBI Funding (Intensive Behaviour Intervention) has been cited as a means of providing long-term skills, particularly to children with Autism. However, what has been available cannot be taken for granted and assumed to be permanent as a result of service sector instability (Bonnett, 2003). This helpful intervention is cost effective in the longer term (CBC, 2006), but therapy and intervention is costly and highly controversial, as noted by the Ontario Association of Children’s Rehabilitation Services [OACRS] (*Families seeking IBI*, 2004), the Ontario government limits funding to children up to the age of six (Lindgren, 2006). Expenses thereafter, are for the parents to assume (CBC, 2006). As a result, many families are not able to manage the tremendous long-term expense. Due to long wait times and a desperate need for financial assistance, some families have moved to Alberta where the province provides services up to the age of 18 (Canadian Press, 2006). Other families have sold their houses to finance the specific needs of the child (Gillespie, *Feisty*, 2007). While either of the aforementioned alternatives may not be a viable solution for all parents, it does raise important questions

about equitable inter-provincial service delivery, the rights to education and special services as well as the desperate measures that some parents will undertake in order to find services for their child.

### *Social Services and Issues*

According to Calliste and Sefa Dei (2000), “‘Western’ society is fundamentally structured along the relations and dynamics of difference”(p. 13). They add that “these structures and practices are contrary to a just and equitable society” (p. 13) To illustrate this in a western societal context, markers of difference include racialized ethnicity and gender and contribute to the gaps in formal service equity in the GTA. Dossa (2006) adds that “combined with other factors, racial ideologies permeate the social system in such a way that persons with disabilities are often perceived to be white” (p. 352). This restricts the participation of many individuals from receiving these services and as active agents in shaping the system. As Doyle and Rahi (1991) state, “too often the human services system has been characterized by differential treatment of newcomer immigrants [which] limits the opportunities for diverse communities to shape policies and programs” (as cited in Siemiatycki, et al., 2003, p. 433).

Organizations can begin to address existing ideologies if the organizations recognize these as connected to whiteness and white privilege. These are all sensitive issues, yet, ethically necessary to address in order to enquire further into the social construction of whiteness, consequential “othering” of groups outside established dominant norms, and the “default to white” (Lopes & Thomas, 2006, p. 145) which is pervasive in many organizations including disability organizations who may or not be aware of this dilemma.

One way to affect change is by broadening an institutions’ self-understanding. Bowers (1984) indicates that this can be achieved by social services building upon reciprocal cultural capital, which involves developing a sense of self-awareness at the institutional and individual level (as cited in Kalyanpur & Harry, 1998, p.532). Such self-reflection, Kalayanpur (1998) states, happens at three levels. The first is the *overt* level, which involves an understanding of cultural difference such as appearance. Secondly is the

*covert* level, which speaks to an awareness of cultural aspects that are not immediately identifiable such as religion or communication styles. Thirdly, on a *subtle* level, is the need for “an awareness of aspects of cultural difference that are embedded, even taken for granted such as our values and belief systems” (as cited in Kalayanpur & Harry, 1998, p. 532).

In order to illustrate this, building on cultural capital involves understanding more deeply the issues and dilemmas, which some immigrants face. For example, it is important for social services to understand the different kinds of fears and valid pre-conceived notions about health and social services, which may be more prevalent amongst immigrants (and refugees) and consequently, may deter service usage. To demonstrate this point, in a case similar to immigrants with disabilities, mothers of children with special needs may also avoid social service and health usage due to the fear of deportation as a result of immigration policy stipulations preventing individuals from making “excessive demands” on the system, as noted in Article 19(1)a (Penafiel, 2001, p. 23).

A greater understanding of immigrants’ concerns, along with the service providers deepened self-understanding would, note Kalaynpur and Harry (1998) improve social service provider’s personal and professional practices as well as their understanding of issues concerning immigrants. This could lessen the divide between service provider and recipient of health care, and thus, engage mothers who (who may be a part of a racialized minority) to participate as active agents in acquiring supports.

In addition to examining one’s personal values and cultural identity which inform relations with parents, professionals have the added advantage of knowing the institutional ropes of getting around a system, and (usually) knowing where to go for help. It cannot be expected that mothers will just know where to go for help (Kalayanpur & Harry, 1998, p. 532). Sharing this navigational knowledge with mothers is an important aspect in helping them manage, and another reciprocal opportunity to build cultural and human capital. That is, her knowledge, navigational and decision-making skills regarding her child’s health, welfare, and security.

Historically, the Canadian post-war welfare system was seen as a social safety net, promising a better and secure future for all Canadians (Brodie & Trimble, 2003, pp. 4-5). However, increased globalization, corporate restructuring, and growing economic insecurity in the 1970s and 80s led neo-liberal elites to challenge the way Canada conducted its governance (pp. 4-5) leading to a devolution of formal service provision. Consequently, the only solution deemed to be effective was “to slash government spending, eliminate the growing deficits of both the federal and provincial governments, deregulate businesses so that (they could better compete in the global market and return government assets to the market where they ‘naturally’ belonged” (pp. 4-5).

A key factor of neo-liberal governance identified by Brodie & Trimble (2003) was privatization and the push towards ‘new public management.’ This public administrative approach rested “on the belief that the public sector should take responsibility only for those things that other social actors and institutions cannot” (Brodie & Trimble, 2003, p. 7). This shift also led to a refocus (on individualization) and individual responsibility in assuming personal risks involved in, for instance, providing for old age, and other home care necessities. The shift to the home is yet another manifestation of system restructuring and privatization (Brodie & Trimble, 2003, p. 7). Increasing “out-patient” home-based settings in the past two decades has thus increased the responsibilities of informal parental caregiving (Raina, O’Connell & Rosenbaum, 2005, para. 3). Currently, while some parents may wish to care for their children at home, the necessary supports may not be there to carry this out and may increase the parents’ (often the mother’s) social polarization in their own homes. This is all because of the deregulation from federal and provincial jurisdictions to the private sector, which is changing the face and delivery of social services in Ontario.

The increased push to privatization has led to numerous cutbacks to formal support service delivery over the past fifteen years, specifically as they relate to children with special needs (Crawford, 2007). Without adequate funding, social services are beginning to collapse. Vital early intervention programs and some disability services are also threatening to close. One executive service provider stated: “We’ve held everything together with scotch tape and chewing gum, but we don’t know how long it’s going to be before it falls apart” (Gordon, 2007).

Already stretched to the limit, research indicates that support centres for children with disabilities will need to grow even more so with the increasing patient lists over the next few decades. In 1990, 7.2% of all Ontario children between birth and the age of nineteen had a disability. The number is expected to increase by more than 15% over the next twenty years as a result of advancements in technology and the increased numbers of “miracle babies” (Witzel & Ormston, 2005, para. 5). An increasing aging baby boomer population will add additional strain to a stretched system and will likely lead to an inadequacy of available services (Medd, 2001; Canadian Council on Social Development [CCSD], 2002, para. 4). What is more, cuts to vital supports will increase mounting pressures within the family unit (Crawford, 2007) putting even further pressure on mothers and families and likely increasing their already complex family situations.

Deinstitutionalization and the developmental sector’s transformation of the service sector includes the heralded closure of Ontario’s remaining developmental institutions by 2009; however, concerns are abound about the future including long waiting lists for available independent housing (Crawford, 2007) and long-term care support. To remedy the situation, under the umbrella of “inclusion and equal rights” inclusive community-based support, the Government has recently designed a long-term care housing protocol jointly operated by the ministries of Community and Social Services and Health and Long-Term Care. The protocol has established that “transitioning adults with a developmental disability in the community and in DS [Developmental Service] facilities [will be admitted based on eligibility] to the long-term care home sector” (*Long-Term Care Access Protocol for Adults with a Developmental Disability*, 2006, p. 1).

Public outcries from families, along with media support have contested this push toward “re-institutionalization” citing the government encourages and facilitates the “placement” of people with disabilities in long-term care, with residents twice their age (Crawford, 2007). Safety, among other issues is one prominent concern given that there is the potential for violence particularly with the amalgamation of individuals with a disability and residents in long-term care facilities. The death of a nursing home resident

in Sudbury illustrates the seriousness of the issue (Croteau, 2007). Grassroots organizations such as Family Alliance have been advocating against nursing home facilities:

we are well aware that adults with disabilities of all ages are being forced to accept placement in long-term care facilities. It is very tragic, but true, that as a consequence of this policy, some 18-year-old persons with disabilities will face a lifetime in a nursing home. (*Family Alliance*, 2006)

Family advocacy groups in Ontario are advocating for public and family input to review the protocol stating that such facilities should not be a replacement for person-directed planning processes. In the United States, similar situations are also occurring where advocacy groups are also fighting the push towards re-institutionalization also considered to be another form of “warehousing” (ADAPT, 2006).

Family life-stage needs vary according to the age, health of the parents (if there are two), and their ability to care for their children independently, and in the future. Their children’s long-term life supports are a concern. Since the protocol is recent, little or no research has been found to illustrate the long or short-term situations that families may be facing, or the way in which immigrant families might be implicated. These recent social service developments raise questions concerning immigrant adults who may also be placed into a long-term facility, in addition to the impact on the individual, the family, and the way in which long-term facilities will be able to accommodate the variety of future residents’ needs.

### III METHODOLOGY

#### Methods and Procedures

The research is qualitative in nature and uses interpretive analysis to explore, at a deeper level, the contexts, and experiences of mothers in the GTA since little information exists about their experiences. Face-to-face interviews were held with the eight mothers in English or Spanish using open-ended or semi-

structured questions. Similar questions enabled me to compare across women's experiences. (See Appendix for recruitment information and interview questions).

The results of the research build upon a small body of literature based on previous studies. These include peer-reviewed journals and catalogued books. A number of other resources were also referenced including NGO material, films, magazines, publications, popular literature all of which contributed to understanding and viewing the mother's situation from both a macro and micro sociological perspective

### Recruiting Participants

After the research proposal received ethics approval, I recruited immigrant women from the Greater Toronto Area (GTA) by a variety of means including postings and electronic mailings on the internet (*Craig's List*, the Centre Francophone "*Babillard*"-electronic post-board) and by means of personal contact through convenience and "snowball" sampling. Service providers were also individually contacted followed by an e-mail including an introductory letter and recruitment poster further explaining the project. Although this was a time-consuming method of recruitment, it proved to be particularly useful for networking with service providers about other organizations I should contact.

### Participants

The interview participants included eight mothers of varying nationalities who were parents of a child with a disability. Five out of the eight mothers had more than one child in the family, but for all of the mothers, only one of their children had a disability. The women ranged in age from the mid- twenties to mid-sixties and all spoke English except for one who spoke Spanish. Four out of the eight mothers had partners, (identified in these particular samples as married). Three mothers were single mothers and one was recently widowed. All of them identified themselves as primary caregivers and provided unpaid care to their children. Five of the mothers were full-time stay-at-home mothers. Since this study was exploratory in

nature, marital status, their age, or the type of disability, which their children had, did not restrict the mothers' participation in the study. Pseudonyms were used to protect disclosure of the mothers' identity.

Seven of the eight mothers were either first or second-generation Canadians and had resided in Canada for more than ten years. Only one mother had recently arrived and at the time of the interview, the mother had recently filed for refugee status. Ideally, the women were to have lived in Canada for longer than one year, but all of their experiences as either first or second-generation were considered and welcomed. The perspectives of the one exceptional refugee mother were of particular interest and invaluable since little has been written in the GTA about refugee mother's experiences with children with a disability. This paper further reveals insights about perceptions of disability in Peru, her country of origin. Her experiences were helpful in cross-referencing the experiences of other mothers and significantly added to the experiences, which all mothers had uniquely encountered.

To maintain confidentiality, I did not interview participant's children. In addition, translators from the same ethno-cultural community were also not sought due to time, and financial limitations as well as the possibility of misinterpretation. More importantly, the comfort level of the participants was important to consider for ethical, and cultural reasons. Another concern was the ethical risk associated with children as culture brokers, an important area of study, which is often under recognized. Jones and Trickett (2005) have found that children of immigrant families are often placed in the role of translator, interpreter, and mediator of important cultural information for their parents. The authors cite examples such as answering the door, or telephone and accompanying parents to appointments as common tasks performed by children and adolescents. Parke et al. (2005) and Valenzuela (1999) have found that children of immigrant families assist the parents' acculturation process, as they interpret important cultural information, but this may also place pressure on the psycho-social adjustment of children and young adults and overall interfamilial relationships (as cited in Chao, 2006, p.271). This is a new field of study and would merit further enquiry particularly as it applies to siblings of a child with a disability.

## Interviews

All interviews were voluntary, and each one lasted approximately one hour in length at a venue of the participant's choice. Interviews were held in coffee shops, in their place of work, study, or by invitation, to the participant's homes. Interviews were digitally recorded and limited notes were taken so as not to detract from the flow of the responses or conversation. The interviews could have lasted longer than the prescribed one hour and some in fact went on for an hour and a half.

One interesting dynamic to note upon first meeting, was the change in participant's attitude after the contract was signed. Some of the mothers were very personable and talked quite freely, but after the signing, a formalized element of the interview, the tone of their disclosures changed slightly and they became a little bit guarded throughout the interview. This may have been attributed to nerves, the formality of reading and signing the contract, the nature of being recorded, (although the recorder was sometimes put to the side to de-emphasize its position), as well as my role as a white researcher, as previously discussed. This is why sincere appreciation for the women's time was demonstrated initially by means of a floral arrangement and a personalized thank you note (including a monetary token). I believe that this gesture helped to reduce some anxiety, if it was an issue, and helped to establish rapport and trust, essential components of interviews.

In addition, mothers may have refrained from providing some in-depth information regarding certain detailed areas of their lives due to some interview dynamics and the interviewer- interviewee relationship: the interviewer was Caucasian and the women, for the most part, members of visible minority groups. The interviewer's role as an academic researcher could also have provided some level of discomfort. These dynamics may not be unusual in interview experiences; however, every attempt was made to ensure a greater level of comfort, lessen the possibility of nervousness and possibly intimidation by providing an ice breaker such as the floral arrangement, or gift. The gift was an unexpected surprise for the women and it was well received. Generally, I hoped that this would help to lessen the above-mentioned interviewer-interviewee divide, which it did.

It was challenging to see the extent to which racialized discrimination played a role in women's lives. Some may have felt reserved into disclosing information due to the sensitive nature of the interview, particularly if revisiting this information induced some level of discomfort. Some of the mothers may also not have realized that they experienced "racialized discrimination," or did not wish to respond accordingly out of pride because they may have felt that it really was not an issue for them at that time or otherwise.

### Data Coding and Analysis

All quotes were written verbatim and the women's actual words were not altered except for contextual clues indicated in brackets. This is an important aspect to acknowledge during the interview process. The text was then checked for accuracy against the recording, analyzed in detail according to descriptive codes written along side the text and then, analyzed further. I did not make corrections to grammatical or syntactical errors.

I then formatted the text into themes and combined them into charts. Secondary literature was colour-coded so as to support both research and interview details. The information was then analyzed using exploratory interpretive analysis documenting the women's experiences as part of the explorative and qualitative design of the study. The interresetional approach considering the variables of gender, racialized ethnicity, and disability created greater context for analysis of the womens' experiences, in comparison to employing only one factor, which would have produced a singular and rather limited perspective of their lives.

### Additional Insights

The opportunity to conduct the interviews in English, French, and Spanish facilitated recruitment possibilities and eight mothers volunteered. Mothers who did not meet the above linguistic criteria were not recruited since interpreters were not engaged in this study for a number of reasons already addressed. What

is further more, I did not seek a family member, friend, or member of the interviewee's ethnic community to translate fearing inaccuracies and above all, a breach of confidentiality within the family and community.

Other dynamics impacting disclosure may have been the level of pride some women may have had in sharing their experiences. Depending on when they arrived in Canada, some of the mothers may have seen the study as an opportunity to talk more about their accomplishments, but in a way that may have taken the focus off of the other daily struggles, which were not disclosed, or minimized in order to emphasize the point of arrival that they were at now. As one mother stated about her past experiences with her daughter who is now forty-three, "time erases memory," so it was difficult to see the day-to-day impact that the caregiving had on this mother during her earlier settlement years. In addition, the focus for this mother had changed as she had moved on to another stage of caregiving.

The perspective of the Peruvian mother did shed light on significant issues regarding disability and immigration. Although this topic cannot be elaborated upon in this paper, it raises a number of issues concerning immigration, disability and disability-related issues, particularly the situation of refugees who arrive in Canada as refugee claimants. Their experience is often frustrating as they wait "in limbo" for their refugee hearing. Another point raised by the Peruvian mother is the determination of a mother's will to provide "solutions" for her child. In the words of the Peruvian mother, "the only way is to confront the problem, not help the problem, [and] look for solutions." In doing so, her situation speaks to the need for greater transparency in the way in which these issues are dealt with particularly the way in which they relate to the discourse on social inclusion, citizenship, and belonging.

#### Meet the Mothers

A brief introduction to the mothers is not meant in any way to encapsulate their experiences in a singular manner; the synopsis merely provides an initial glimpse about who they are, their children, families, their concerns, issues and their joys. The synopsis also creates context for the women's lived experiences and provides further understanding of their lives since immigrating to Canada. To follow are

detailed quotations to all ten interview questions. The findings will be presented in themes and discussed in further detail, which will follow the discussion.

Mother number one recently came to Canada as a result of domestic violence and her son's disability. Her reason for leaving Peru included her vision of a future for both herself and her adult son with mild Asperger's Syndrome. After arriving in Canada, she applied for refugee status and at the time of the interview was living without status. Inspired by her understanding of Canada as a country that she believes to be "accepting and tolerant of disability," she hoped to find "refuge in the city" (McLean & Young, 2007), in the way of economic opportunities as well as a future for her son. As a professional psychologist, she immediately began volunteering with an immigrant-serving agency by preparing and co-presenting workshops on emotional well-being for Latina mothers. At the time of the interview, mother number one was living in an indefinite limbo as her claim for refugee status waited processing. Since this mother's caregiving, experiences were in Peru she did not directly encounter linguistic or cultural difficulties often experienced during settlement. However, due to domestic violence and her economic situation, she did have to relocate within various cities in Peru on a number of occasions, which was distressing and involved displacement and resettlement within Peru. Mother number one's interview was insightful, rich in perspective, and provided many unique yet similar experiences to those of the other mothers.

Mother number two emigrated in the 1980s with her family from Dominica when she was in high school. She completed her post-secondary education in Toronto and worked as a professional in her field. Mother number two is a single mother and has one child, a six-year-old son with Autism. He is non-verbal and is now attending a mainstream public school. She found that the inflexibility of work and the on-call demands of caring for her child prevented her from sustaining full-time work. At the time of the interview, she was a full-time stay-at-home Mom. She has some family members here in Canada, but does not feel supported. She expressed concerns about wait times for formal help and the lack of continued funding for special behavioural programs for her son.

Mother number three emigrated with her husband from Iran in the 1980s at a time of political instability. Her eldest daughter, now twenty-six years old, has an unidentified disability. Her two other daughters attend post-secondary school and she is very happy that her eldest daughter is now able to achieve some post-secondary education. However, Mother number three expressed concern over the lack of transparent and continuing funding initiatives and opportunities in mainstream and post-secondary education. Mother number three has some extended family here in Canada with the remaining family members in the United States and Iran. Her primary support is her immediate family. Among other activities, she has created her daughter's placements in the absence of available programming.

Mother number four emigrated from Sri Lanka in the early 1990s. Her daughter has Down's Syndrome and is currently eighteen years old. She has a younger son attending post-secondary education. Mother number four has some family members living here who initially sponsored both her and her family to come to Canada. Mother four had to return to school to find employment in Canada. She currently works full-time and cares for her family and daughter. In the past, she cared for her aging mother in the GTA and her in-laws overseas. She is very concerned about her daughter's future placements and living arrangements when she is no longer able to take care of her.

Mother number five is a second-generation Canadian of Chinese heritage. She is married and has a six year old son with Autism. Although she worked for a number of years as a professional in her field, juggling her child's current needs with those of her family requires her to stay at home with her son. She strives to keep on top of all of his medical issues and paperwork and would like to do more for him, but feels stretched trying to manage the family's day-to-day needs against the needs of her son. As the eldest daughter in her own family, she feels anxiety about not being able to provide more support for her own parents who are aging and have on-going health problems.

Mother number six immigrated to Canada from Grenada in 1995. She returned to school in Toronto juggling both academics and employment supporting her mother and eldest son in Grenada. Just after her second son was born with Autism in Toronto in the mid 1990s, her first son, age fourteen,

immigrated to Canada joining her after eight years of separation, but has since moved out. As a single mother, she provides full-time care for her four year old son with Autism. Mother number six worked as a professional in her field, but needs to stay at home in order to manage her son's many appointments and fragile medical condition. As an only child without supports in Grenada or here in Toronto, she concurrently manages her mother's complex nursing home care in Grenada from her home in the GTA. She feels tremendous anxiety trying to manage her multiple caregiving tasks of looking after her sons in Canada and mother in Grenada. As a result, her health has been affected.

Mother number seven is a first generation Canadian from El Salvador. Both she and her family were public figures in various democratic activities and escaped threats of persecution. She fled with both her husband and two children, escaping into the United States, after which she sought refugee status in Canada. Her qualifications were not recognized and both she and her husband were required to retrain in another profession. She now works full-time and has four children. One of her son's has Asperger's Syndrome and is currently attending post-secondary education. Her extended family currently resides in the United States. Contact and support from them is limited.

Mother number eight is a second-generation Canadian whose parents emigrated from Hungary in the 1920s. Mother number eight has three children, the eldest being her forty-three year old daughter with Autism. She was always a stay at home Mom. Although her parents were very supportive, they are now deceased. She has some family residing in the area – a brother and sister-in-law, which is of some help now that she has been widowed for three years. Mother number eight initiated a number of community programs for integration in the 1970s and 1980s. She felt that these integration initiatives planted a seed for positive societal and educational changes. She is currently deeply concerned about future long-term living arrangements for her daughter when she is no longer able to care for her.

#### IV FINDINGS AND DISCUSSION

Overall, six organizing features emerged from the findings: settlement and the impact of immigration; informal networks of support; formal networks of support; the lack of transparency of information and services; future concerns, and personal factors. All of these categories include sub-sets of information, which will be addressed in more detail. The paper builds on a number of studies particularly on the findings of Stewart et al. (2006), Neufeld et al. (2002), Raina et al. (2005) and Burton et al. (2006). Similar trends were identified in the results of this paper confirming the lack of support, which immigrant mothers were facing at a familial and community level. The results build on these previous studies confirming that immigrant mothers, and particularly single mothers as caregivers of children with special needs, are marginalized and face a number of barriers to formal and informal social support.

In addition, this paper supports these previous findings highlighting, in particular, the need for greater social service awareness and collaboration in order to assist not just the child with a disability, but mothers (with their multiple caregiving roles), and ultimately the family unit. Other findings in this research paper which address and expand upon the findings of these other studies were the additional responsibilities of caring for aging parents, the mother's own future age and health limitations in caregiving and barriers to caregiving support. This paper's results continue to shed light on immigrant mothers' complex short and long-term needs and how these needs can begin to be met and sustained.

## Settlement Barriers and Impact of Immigration

Four mothers stated the impact of pre-migration upon their settlement. One mother was sponsored by her family here in Canada and did not state that any significant difficulties impacted her situation at the time. On the contrary, two other mothers were affected by political regimes forcing them to leave their home country (one from Iran and the other from El Salvador). Of these two, one mother mentioned that she was targeted by her government as a result of her feminist activism and therefore, fled for her life. Long after arriving in Canada, she suffered from what she called “persecution nightmares,” which, combined with other settlement stresses, began to affect her physical health and ability to care for her child, and family. She stated that these factors also affected her mental health as she suffers from “self-blame.”

The pre-migration context for another mother involved immigrating to Canada due to economic reasons while simultaneously providing financial support to her mother, and first son in Grenada. Her experiences were stressful and reflective of what is commonly known as the “sandwich generation.” She provided this ongoing care in a singular role as she stated as both “Mommy and Daddy.” Such dual responsibility is not recognized widely enough in Canada particularly as it primarily impacts both first and second-generation immigrants who continue to support family members in the GTA and/or internationally.

The complexities of arrival, disability, and settlement were multi-faceted for many of the mothers. Some mothers were not impacted by their child’s disability for a number of years after immigrating and until their child was born. In the case of one other mother, her child had not been assessed for a disability at the time of immigration, so it was not an issue for her. One mother had immigrated with her child who had a disability, while another mother, who is a recent refugee, is waiting the processing of her papers. The mothers’ situation will be discussed shortly, but identify the mothers for whom disability was a significant issue at the time of arrival.

A significant component of arrival and settlement is social capital and social inclusion as identified by Caidi and Allard (2005, p. 3) which is one issue that was raised by the mothers, particularly as it related to the availability and sustainability of family supports. Some family members had existing family supports in Canada that were helpful to some degree. However, it could not be assumed that family support would provide the basis of all settlement needs to all family members and that this support would continue into the long-term. As one mother stated, family settlement support was helpful, but buckled to some degree as a result of tension and expectations upon the host family: "...he would blame my sister ...[he felt that] she should have researched much better, informed us better what was going to happen to my daughter once we got here, which I think she had no control of." This mother recalled that at the beginning, "it caused a lot of stress." How family supports are sustained in the face of disability and immigration is another area of interest, particularly since the immediate and extended family unit can play an integral role and help to build social networks of support.

In addition, the needs of mothers, fathers, and the family are unique and should not be homogenously linked together. Consequently, additional questions can be raised about the way in which gender differences play a role in settlement as one mother stated, "women tend to transition more easily than men. It took him [her husband] a while." From a disability perspective, looking at the different short and long-term ways parents as well as siblings settle (acculturate) would provide a more holistic understanding of the family's needs requiring the attention of policy makers, service providers, and other front line workers.

Although three out of the four women negotiated a diagnosis for their child's disability after arriving in Canada, another mother encountered thirteen years of paper work in order to have her daughter admitted and "accepted" to live here in Canada, even though the rest of the family's paperwork had already been accepted. The cost of psychological assessments and thirteen years of constant paperwork caused much uneasiness for the family. Living in a state of limbo was difficult, as they did not know if they could stay, or if they would have to return home because of their daughter's situation. She remembered:

We were given a Minister's permit. It wasn't even explained to us what it was [at the time of emigration in 1993]. Therefore, when we came here, after three years, my son, my husband and myself were given landed papers, but not my daughter. They said that it was because of her disability and that she had to do further medical testing before it could be given to her...At the end of eight years, she had to do psychological assessment which we had to spend almost \$900 [including] a series of appointments...at the end of it, there was a huge report sent into immigration. Finally, after almost ten years, she got her landed papers, so it was actually thirteen years before we got our citizenship here in Canada. It was that long.

The mother questioned the government's request for a psychological assessment when she stated that they "knew" that her daughter had Down's syndrome. She also felt that the assessment was a "waste of money" and an expense that her family, as new immigrants could ill afford. Assessments and medical criteria are important elements to consider particularly as they relate to immigration, in particular, the lack of transparency concerning system operations and other issues related to disability, which have not been widely addressed in Canada. Some questions remain unanswered. Who gets in? Why? How? and with which disability, if at all? Specific immigration policies will not be explored in depth in this paper; however, the experiences of this latter mother highlight some of the concerns outlined by Penafiel (2001) concerning immigrants' fear of deportation for creating an excessive demand on the system. Living in uncertainty, one mother felt that her daughter was subjugated to unnecessary and costly tests and much paperwork, which, if not accepted might lead to an uncertain future for her daughter and the rest of the family in Canada.

As mentioned in this previous example, bureaucracy figured prominently in six of the eight interviews. As new immigrants, many of the mothers cited the ongoing difficulties of paperwork, which did not seem to let up in the long-term, depending on the needs of the child. As one mother stated: "March was a difficult month as paperwork was due at that time...it was really difficult because we were just trying to establish ourselves so we didn't have flexibility with our job." It was particularly onerous for the first generation mothers who were required to pay out of pocket for doctor's reports, a myriad of other medical

information, extra tutors, and assessments: “I had to work harder, to pay all of this...as a new immigrant. And [on] family, [there] was more pressure, and when [there is] more pressure, it is harder...and stressful on the family.” An exception was made by one second-generation mother who stated that she had very little paperwork since her child was diagnosed in the 1960s at a time when mental retardation was the umbrella term for intellectual disabilities “...it was just accepted.” Present day administrative pressures were outwardly experienced by six of the eight mothers who found the pressures of keeping up with “the paper work” to be very stressful. Exasperated and drained, one mother added, “The government *loves* paper...[long pause]...[but] they probably don’t look at any of it.”

Some of the mothers experienced language, accent, and interpretation difficulties upon immigrating to Canada. In the case of two mothers, language issues created road blocks to accessing formal services. These findings coincide with those of Stewart et al. (2006) indicating that while language was a recognized difficulty, personality, opportunities, and cultural views placed on the value of learning English determined to some extent the rate at which the mothers were able to learn the language.

Accent posed another problem that was not elaborated upon by the women in this paper, but could also be explored further in the way it relates to impeding an immigrant’s access to services. One mother stated that on one occasion she felt that she was refused telephone assistance because of her accent. “I had this lady, she was helping me, but it wasn’t much help because I was telling her that whenever I call the board and they hear my accent ‘click’, they cut me off.” Even though “the lady” encouraged her to call: “They want to hear from parents...” the mother felt that “they [didn’t] care about the parents. They didn’t want to listen to me [and] they wouldn’t even give me a chance to speak.” This mother felt that she was discriminated against because of her accent. She also cited that constant advocacy for one’s child can inadvertently categorize the mother as a “problem parent” thereby creating additional barriers to support. Both language and accent-related concerns contributed to her anxiety as she battled categorization issues. She felt that such labeling further hindered her from obtaining the supports that she needed.

Two of the mothers were determined to learn English for the sake of their children and persevered to look for ESL services in order to avoid interpretation issues. However, prior to acquiring enough English, both mothers stated language difficulties as significant communication barriers, particularly at school meetings and with medical doctors. Even in the case of one mother who “was a nurse back home,” the lack of interpreters was very frustrating as she was not able to independently communicate concepts to the doctor in a way that she felt she would be understood. A reliance on outside interpreters depersonalized her situation and risked the misinterpretation of facts. Schools were also an issue where she had to bring her own interpreters, “people who didn’t speak English well either.”

The women had post-secondary education and were articulate, even though English was a second language for some of the mothers. The lack of time and navigational knowledge were significant issues for all of the mothers. For the mothers who had been here for more than ten years, web information was not accessible to them since they did not have a computer. These mothers relied primarily on word of mouth and information from other mothers emphasizing the critical importance of social capital networking as a means of obtaining information and social inclusion as an outcome.

Even though a number of the younger mothers had access to, and utilized their personal computer, they felt that it was not an adequate substitute for in person informational and personal support. Furthermore, they stated that they were not always able to locate the information, which they needed. This illustrates that immigrant women may remain information poor and isolated from the supports that are needed as illustrated by Caidi and Allard (2005). Although technology is improving, computer supports are not readily accessible to many mothers due to language, inaccessibility, and navigational difficulties. This lack of support emphasizes the need for continued outreach services to assist parents who might be most marginalized because of these mentioned issues. Knowing where to start is vital to helping mothers and their families and was another significant issue for this latter group of younger mothers: “Even now, he’s not here, [but] I always have something around to do...I don’t even have time to go on the computer.”

Similar to Neufeld et al. (2006) transportation was also a significant issue for the mothers since the majority of them did not drive and relied on public transportation to get to appointments, to their child's day care, or school facility. While the cost was identified as one factor, taking the TTC often proved to be onerous since the child's unpredictable behaviour could potentially put him or her in danger. In addition, the public's attitude often added to the mothers' stress. On many occasions, mothers stated that they took a taxi to get to the day care or to doctors' appointments and cited the lack of time and convenience as the most significant factors. Two mothers stated that when they were sick, or overburdened, they ended up using taxi services which consumed their financial resources: "I have no one else...it meant that I have to take a cab to drop him off and come back home and when you look at it, it is all money, you know...money I can use elsewhere...for other things...[it] could go toward some food or some much needed stuff." Only one mother said that she was lucky to receive private transportation from a volunteer service provided from a service agency. The service catered to an extremely limited number of clients, only a few children were able to avail of the service despite numerous appeals from other mothers: "some moms have to TTC with their sons. It is very hard time consuming, exhausting. I don't have a license... [but]...I am trying! [but] I can't study well enough to concentrate!" She further notes the lack of transportation services was a significant financial stress for mothers in general.

De-skilling, the lack of recognition for their foreign credentials, was another reality which four out of the eight mothers faced as after they had immigrated. Returning back to school in order to retrain was a very disheartening process for the women adding to their settlement difficulties. It was also difficult to manage because the husbands of two of these four women also had to retrain adding to the complexities of economic insecurity and family life, which was a constant family juggling act.

Other de-skilling situations included "loss of time" as stated by one mother. One mother immigrated here in high school, and proceeded to acquire a University education in the GTA. Despite such qualifications, she found that the full-time responsibility of being the sole caregiver for her son prevented her from holding down a job for which she was professionally trained. Consequently, she stated that she was "behind" and would, therefore have to retrain in her field. However, time and opportunity prevented

this from happening. In addition, the attitudes of the social workers proved stressful: they did not truly recognize the stress of her existing day-to-day work in the home and overall family situation. This mother felt pressured to undertake volunteer work, to demonstrate productivity while on social assistance. Yet, her parenting and day-to-day work seemed to be invisible to others. The mother was unable to find the time to volunteer and would like to have re-skilled in the field of her profession, but felt that the assigned social worker did not take the time or make enough effort to understand her situation and help her find the appropriate outlets and resources which she needed.

While four of the mothers were able to work for differing periods, two opted to stay at home, as their husbands worked. Of these two mothers, one felt it was best if she stayed at home in order to care for her son and the family while the other stayed at home because her husband wanted her to do so. In this latter case, the mother was content to stay at home for this was the norm during the 1960s. In the remaining cases, two mothers were not able to work because of the pressures affiliated with being the sole caregiver for their children. Questions related to their overall financial status were not raised, although some mentioned that they had medical insurance which helped; others mentioned many occasions when it was difficult to get by on what they had particularly when they had to pay for specialized assessments, doctor's paperwork, regular taxis when the TTC was not an option, or when the mother was ill. These issues were especially pressing when her child's unpredictable behaviour posed as a potential danger.

Four out of the eight mothers in the study mentioned financial difficulties as a source of strain in their lives. Three of the four women were single mothers and had to re-skill in order to find employment, but since they lacked informal help at home, they were prevented from being able to retrain or return to full-time work. In addition, the three single mothers cited inflexible work schedules as other deterrents in engaging in any work. Two of the three mothers cited health reasons preventing them from returning. They noted that their overwhelming responsibilities contributed to their depression which confirms studies by Plant and Sanders (2007) as well as Olsson and Hwang (2001) indicating that the long-term parental health of caring for children with chronic disabilities has an impact on long-term parental health, particularly as it affects higher rates of physical, and mental health problems. Although it cannot be determined that single

status of the latter three mothers reduced their family situation to one that was impoverished, particularly since they were unable to work, combined financial pressures may have contributed to economic disadvantage rendering them at risk and vulnerable to socio-economic and health problems at an earlier age. These findings are supported by the study on the healthy immigrant effect (Hyman 2007, p. 26). Further studies on single mothers could illuminate additional findings concerning their overall situation.

The mothers did not mention housing as a significant issue, although it may well have been a socio-economic concern as it pertained to the overall quality of the living situation for the women. Three of the mothers expressed concerns over the limited space in their apartment building preventing their children from playing inside the building. The lack of appropriate play areas was problematic particularly since the mothers expressed that their children's high rates of energy necessitated "appropriate and supervised" (child-friendly) outlets for physical release. Such facilities were not available to them. The small space in which the families lived did not meet the children's' needs either, but rather, exacerbated behaviour problems. Social contact was another issue raised by one mother who could not let her child play outside unsupervised. In order to increase his social skills, she often sat with him in the lobby of the building so that the residents could interact with her son and her family. Alternative living arrangements may have improved the child's social contacts, but since such opportunities were limited, the mother felt settled in her residence since it was close to the daily amenities of grocery shopping. Overall, many of the mothers felt restricted by their housing situation.

### Informal Supports

Informal networks of support such as faith groups, parental support networks with other women, and immediate family were cited as significant support. All of the women stated that their faith was significant in some way, whether they were part of an organized faith community or not. The comforting spiritual connections were not limited to formal attendance. Some experienced religion by watching "TV on Sunday mornings," spending time alone with their beliefs, or having others pray for them.

Parent support groups and contact with other mothers provided the most significant source of informational support for four out of eight mothers, three of whom were younger mothers. One mother stated that parent support groups, in particular, groups with other Moms, was the most important support for her as she was a single parent, and found it difficult to cope by herself. Another mother emphasized the draw and attraction of a “Mom [of and autistic child that she] is meeting for the first time. I feel that she understands me just on a first meeting.” The fourth mother who was in her sixties stated that she found the support groups helpful during her daughter’s early school years, but did not think that she needed them now as a result of the pressing need to find appropriate long-term housing for her adult daughter. This mother did not know where to turn for help concerning long-term living arrangements for her daughter.

Similar to Neufeld et al. (2002) immediate family supports including the husband, and or other children were also cited as the most important source of help along with internal support for four out of eight mothers. One second-generation mother stated that family support was not questioned; it was part of the norm: “We lived with our family, there was no indication that it was hard. In fact, on the contrary, it was extremely supportive.” For the other second-generation mother, family support was not that significant since she lived apart from her family. Sibling and parental support was “minimal” since her siblings had their own families and her parents or in-laws were either still working, or occupied with their own health problems about which she felt guilty.

Three of the mothers experienced what they considered no “concrete” help from their extended family who lived in the GTA. One mother claimed: “they call off and on. Yeah, you know, they call, but still I don’t feel like I’m getting the support from them that I need!” She further cites mobility and age as determinants preventing her mother from assisting: “...If I leave him alone with my Mom...he’ll do all these things that he don’t usually do with me. And she’s like in her 70s so she can’t really chase him around...upstairs and downstairs. She can’t take that.” These three mothers lacked family in Toronto; their relations either were in the United States or in their home country and therefore, these mothers lamented the fact that they were so far from family. The mothers also expressed mixed feelings as some felt emotionally torn and guilty since their family’s attitudes were not always supportive of their child or of

their parenting styles. Regardless, the concept of family was an important element to all of the mothers who noted the absence of practical help and for some, emotional support, whether they lived in close proximity to family or not.

Grandmothers held a prominent role since all of the mothers mentioned their own mother on more than one occasion. The mothers all had varying opinions on the support, which the grandmothers could, or could not provide. Some mothers expressed sadness at being so far away from their own mothers. This sadness was shared by participants who had mothers living in the GTA, yet who could not receive their help because of distance, lack of accessible transportation (the mother lived in the suburbs, but because of her health, could not take the bus, and had to be driven). Other contributing factors were the grandmother's apparent lack of understanding of her daughter's situation. A number of mothers expressed sadness in not being able to emotionally connect with their mothers or siblings. They therefore felt distanced from them physically, as well as emotionally, and felt socially excluded from the family supports that were once so strong.

Leung and McDonald (2001) note that the additional domestic and caregiving help provided by grandparents can be a "bonus" provided that the grandparents remain in good health and independent (p.1). For some intergenerational households, as cited earlier, such additional help can be very supportive as demonstrated in the case of one of the interviewed mothers. However, over time, and due to ill health, the grandparent may in fact be the care recipient and therefore, an additional receiver of care, as opposed to giver of care. In addition, in many cultures it is the expectation that the women in the family are to provide care, whether they are single, or married with family (p.1).

Similar to the finding of Leung and McDonald (2001), in this paper four mothers cited caring for parents as another major challenge. Overall, all of the four mothers were still expected to care for their parents in some manner, whether the grandparents lived in close proximity to their family or internationally. In terms of responsibility, one mother state that she now had the dual responsibility of providing for her child and her eighty-two year old mother who required "...a lot of help and

support...doctors appointments, her knee, groceries, laundry...” This point illustrates yet another layer of settlement compounding the social, emotional, and economic difficulties, which many immigrant mothers may endure. Their family situation may even be more strenuous should the grandparent depend upon them financially, and for their health care. Again, the family’s socio-economic situation can be significantly impacted since many immigrants may not have insurance and may not be eligible for certain social services if their family member immigrates under the “family class.” As well, immigrants’ informal and social capital networks of support, which many are assumed to have (since many are sponsored or have relatives here in the GTA), may not be sustained by their extended family, their own ethnic community, or other mainstream organizations. Recognition is needed concerning the multiplicity of issues contributing to the social exclusion, which families face, and calls for greater employer flexibility, caregiver support groups or compensation for the amount of private unpaid informal caregiving services which families, particularly women, provide in the private sphere of their homes.

Caring for parents can take its toll on mothers. One mother cited tremendous guilt and felt torn between caring for her own family and the needs of her parents. As the eldest daughter of Chinese heritage, she engaged in culture brokering when she was growing up, which was demanding. This observation elaborates on the cultural brokering findings of Chao (2006), Jones and Trickett (2005), and Burton et al. (2006) regarding the continuing expectation of providing simultaneous care to both parents, her own family, and specialized needs of her son: “I used to help them [her parents] a lot...I was the administrator...before my son was born. Now, since they are getting older...there are health issues that arise... for both of them... [long pause and tears]... I feel guilty not doing more for my parents.” This example demonstrates that certain rooted family connections and obligations may not necessarily change over time, or over boundaries, and that managing these complex situations, as well as the needs her own family, are areas not often understood by social service workers, or society.

As the youngest in her family, one mother felt guilty for not being able to help her parents, although they now lived in the United States: “God forgive me for not being more helpful with my parents.” She added that gender roles also play a significant part in El Salvador and in her culture and notes

that although, the women typically help out with the caregiving of aging parents, her parents now rely on the support and proximity of her brother, who is “the only man in the family and a doctor.” She felt ambivalence towards her family situation because it was understood that the five girls in the family would “get married... [and] who cares!” At the same time, since her family does not understand her son’s disability, she has had limited contact with them and notes that since they cannot “see Autism,” they therefore think that there is nothing wrong.

Wong’s research in Toronto (2000) has looked at the responsibilities that women have for sustaining homes within the GTA and immediate and even extended family across national and international borders (as cited in Aguiar, 2006, p. 204). Wong adds that the “double burden” (p.204) on women (who may be the only person to immigrate) affects their social, economic, and psychological states. Maintaining their familial responsibility also affects their health as they juggle parenting in the GTA, or in different countries. One mother experienced the economic impact of her responsibility as she financially supported a son and mother while working here as a nurse in Canada. This mother was separated from her mother and son for eight years. Her son joined her in Canada, but now that her: “big boy [is]not at home” the double caregiving duties and expenses mount: “I am an only daughter and my Mom has been sick for the past year.” She adds, “It is a more demanding situation as she is at a nursing home...even hiring someone down there to help out is difficult...I trusted someone there to do for me... It is hard to juggle between my mom’s health, my son’s health and my health.” However, she mentions that: “[she] had reassurances that it was a nice place.” But, she discovered the opposite, “it is a place plagued with problems...I am the one who is paying for the doctors’ visits and assessments. Plus I have to buy her supplies because...you have to have your own personal supplies.”

In another situation, one mother expressed the challenges of providing care, although somewhat indirectly, to her in-laws overseas: “...also my husband had an ailing mother, who just passed away recently in India ...[pause]...he had to support her both financially and otherwise. So phone calls back and forth...he had to go back every year and a half, so that was quite an expense...a responsibility....[pause], not a burden, a responsibility.” She mentions the difficulties of managing everything on her own while he was

away. This points to yet another layer of settlement that compounds the social, emotional, and economic difficulties, which many immigrants may face. The lack of insurance poses other problems particularly if the family members are not eligible for services for ten years (if their family member immigrates under the “family class”), or don’t have the back-up support from their own community, or other mainstream organizations, either here, or overseas. These examples illustrate the multiplicity of issues affecting families and calls for greater employer flexibility, caregiver support groups, or compensation for the amount of private unpaid informal caregiving services which families, particularly women provide to both older and younger family members living here, or overseas.

Transnational parental caregiving for aging parents is an important topic requiring further study and support as it significantly impacts mothers in unique ways, particularly their physical health and well-being as in the case of the mother from Grenada who was an only child and without family both here and in Grenada. She felt overwhelmed having to manage her responsibilities on her own. Her limited social supports here provide her with some support, but as she states: “Especially now sometimes, you just need that other person to be there, to talk to, to help you...even though you are not in a relationship, still, just having someone to be there...[long pause]...I feel like just screaming! You just go through the emotions and there is nobody there. There is no shoulder to lean on.” Her situation emphasizes the difficulties and lack of recognition of a mother’s social exclusion, which single immigrant mothers face, particularly in their isolation from family as well as ethno-specific supports.

All of the mothers stated that they had no support from their ethnic communities for various reasons including lapsed time and distance from the ethnic groups. One stated that “time erases memory,” and hence she did not feel a strong connection to her cultural community. The second woman felt ostracized because of attitudes in her community towards her child’s disability. The remainder of the mothers, all of whom were first-generation, cited the communities’ misunderstanding of the disability, which prevented the family from making or maintaining supports. One mother stated, “You feel bad. More than anything, you feel, you suffer...because of people’s incomprehension and through this suffering, a mother, raising her child also suffers...[long pause and tears]...It’s like that.”

Another mother explained her community's reaction to her child's disability, which was also impacted by societal attitudes. She said, "...he would be the crazy guy in the block ...in our country, they are not mean..., but they don't care about them because the government doesn't put any effort to help these people have an independent life." In some countries, disability is also associated with laziness. In this case, the mother mentioned that harsh measures or shock treatment using harsh language is somehow perceived as a way to get them to overcome their disability: "...one of the beliefs [that] in our culture, we have, is teach him by using bad language. Teach him to swear and you will see how he will start talking. ...because he is smarter than you." This is another way in which social exclusion affects both the individual and family since disability is often seen as a physical impairment, which can be overcome, if one just "tries." Again, this attitude is pervasive particularly if the disability is invisible.

For children with an invisible disability, such as a learning disability, additional pressure and angst may stem from outside family members pressuring the family into maintaining one's culture and language, which creates another settlement layer as parents negotiate ways to maintain the culture in a non-pressured manner. One mother noted that her family and friends wondered, "why we are not teaching him to speak Spanish?" The family decidedly switched to English as the main language of communication in order not to confuse her son who had a disability. Switching languages is another prevalent concern facing parents who may have made the difficult decision to speak only English, in order to facilitate school, and other outside intervention sources for the children, and the family. Other problems may result since language instruction for service intervention programming often involves English or French as the core language of instruction in Canada raising conflicting issues for families of children with disabilities whose home language is not English: What are the pressures and accommodations that are made for families with a child with a disability who find themselves in this linguistic dilemma? It is a topic will not be addressed further, but is relevant as it does affect many families whose primary language falls outside the parameters of formalized assessments and specialized classes conducted primarily in English or French. Mothers may face further exclusion and isolation from obtaining the supports, which their child need if they do not speak either of these two official languages.

For the mothers, having sympathetic friends and associates proved difficult "...some people dropped you as friends because they didn't know how to handle it, or you know, they thought that their children would catch what our daughter had...[long pause]... gross ignorance." Their experiences were compounded by accusatory sentiments of friends within her culture:

I think that the basic cause [perception of disability in her culture] is that there isn't much openness at all within the same culture... I've had people from my culture give me all kinds of comments about why I had a child with special needs. Oh, ...you must have been drinking. You must have been smoking, so a lot to do with the lack of knowledge.

Another mother cited proximity of cultures as problematic. Even though you are in Canada, there is still the possibility that this can affect your family in some manner either here, or in your home country: "We come from a very small country and it ends up that we know this person somehow. So people are not too comfortable about it...and [there is a] lack of knowledge." Such strong community feelings may deter parents from accessing supports. Other reasons might include the communities' attitudes towards the family who in their opinion, treat the disability as an illness and a problem, which concerns the family nucleus and not just the individual. Families therefore may be perceived as somehow "tainted." Such perceptions are not uncommon and may have a transnational impact particularly on family members in the home country who may not be eligible for marriage given the precedence of family-related disabilities.

Some cultural perceptions of disability might lead other families to hide their children in order to prevent shame from compromising the family's honour, which may, or may not be culturally specific. In certain Asian cultures, the role of honour ranks highly and is often reflected in both the women and children. Since women are often seen as the natural nurturers, and bearer of children, they might be blamed for having caused the disability; on the other hand, they might internalize these feelings and engage in self-blame thereby, compromising their ability to seek help. These gender and cultural dynamics are important for social service providers to bear in mind particularly in trying to help all of the family members. All of the mothers who were interviewed were highly dedicated to their children. Some were often weary, and ill

from the pressures of caregiving. However, it is not known to what degree the role of 'honour' played in their lives, and how this could be interpreted, even though one mother mentioned the importance of fulfilling her "duty" to her family. Exploring commitment, honour, and cultural perceptions of caregiving would be an interesting ethnographic dynamic to explore, particularly as many of these are unspoken dynamics affecting the lives of mothers, their children, and the family unit.

Both of the above mentioned the second-generation mothers had similar experiences concerning their ethno-specific supports. One of the two mothers stated that she received no support from the Hungarian community in terms of support for her child. Another mother, who considered herself to be "Canadianized," did not have much contact with her ethno specific community either. She felt encouraged that the Chinese community was beginning to develop a limited understanding of disability since there was now a name for 'autism.' Support in any form would have been appreciated, but she did not receive any.

Furthermore, as mentioned above, her overall desire was to provide her son with a happy life. She recalled her own childhood memories and the cultural activities in which she participated. These gave her great joy. Tearfully, she stated her sadness in being unable to give her son the same opportunities such as "the wonderful childhood" that she had had as a child. This regret could also recall pressures of being a good parent which could be partially due to cultural and personal expectations of mothering which is a similar finding to what Burton et al. (2006) found in their study.

Along with other mothers, this most recent mother also cited inaccessible cultural activities as a barrier to involvement and participation since they were in enclosed settings and as a result, her son's unpredictable behaviour would not permit them to attend for any length of time. However, she remained optimistic during the interview and tried to relay positive elements of change from a cultural perspective:

I know the name for *Autism* in Cantonese...so when I mention it some people seem to have heard of it, but don't know much about it. So, there is a name that exists. Maybe they also associate it

with mental retardation... because it is a new word, Autism. So a lot of people say that oh, if his brain is in question, they think he's retarded.

If new terms are entering into a specific language, this might help to illustrate that to some small extent, there might be a greater understanding of specific related disability issues, particularly Autism. This is important information for service providers to know since there is both positive and negative power in language, which would help to build upon service providers' cultural understanding of the way disability is perceived in different cultures. This understanding in some way could consequently help them to make greater connections with their clients.

#### Formal Supports and Lack of Transparent Services and Information

Five of the eight mothers cited that they wished that they could avail themselves of respite services, but that significant trust issues prevented them from truly benefiting from it, if they were even able to obtain a spot, given the long waiting lists in Ontario. Cultural factors also inhibited some mothers from availing of respite services since they felt that it compromised their ability to be a good mother despite having need for the service. This latter point is supported by what Porter and McKenzie (2000) describe earlier as the fear of failing to fulfill their role as parents. (p. 99). As a result, if a mother is not able to avail of essential respite services, or other support, her health could be affected leading to other problems and to a potential family crisis.

Some mothers did mention that they received some support from their family, which was helpful; one mother mentioned the effectiveness and support from "a really good social worker." This discovery supports the findings of Neufeld et al. (2002) who note that contact with a specific service support can often provide an essential link to other supports. Other mothers recognized some helpful supports, which provided key networks to other service agencies. However, a number of mothers (particularly mothers of children with Autism) mentioned that sustaining the support was problematic. One mother felt that she was able to receive support from an organization once her child was receiving services, but after the funding

ceased, “she didn’t know what she was going to do” and did not know where she had to go to seek out other options and support for her child.

Similar to Neufeld’s study (2002), all of the mothers in this paper faced barriers in accessing the supports they needed for their child in many unique ways. The findings of this paper found similar results in that the majority of the mothers lacked access because of a lack of social networks, language barriers, and lack of information. Six of the eight mothers also stated the lack of transparency regarding the types of services and available information, which continues to pose serious issues. In one mother’s opinion, “the government has this program so families don’t suffer. But they *don’t* tell, they *hide* it from families who *need* it.” Trying to acquire the supports that they needed, while that information was not always passed on, was cited to be one of the major setbacks for the mothers. One mother reported:

I noticed in terms of any support, especially in terms of funding, [if] it was available...I felt that they were aware of it, but it was not always disclosed to us...being new to the country, there were not internet facilities...I really relied on other people to tell me stuff. I don’t think that there were many resources or information available.

These experiences continue today adding to the lack of knowledge about available present and future supports, particularly for mothers whose children are now young adults and out of school:

From what I have heard from other parents, I don’t think that there is much available... either there are waiting lists or there isn’t much available...She has progressed so much over the years, I just don’t want her to lose any of it... I would like her to be kept occupied all five days of the week and I don’t know if I am going to be able to do it, afford to do it...somebody said...they pay \$50 a day to send their child to a workshop...I don’t know. These are all at the back of my mind.

Also, one mother stated that filling out paperwork without the knowledge of existing supports (in addition to language supports) was a huge knowledge barrier:

I didn't know if you checked off something wrong you are going to get a lesser amount...either have it translated or simplified as much as possible because not everybody has the literacy level to understand all of those questions...and if they could go to one place...maybe that is something that needs to be given out. [Giving] information on resources as opposed to them venturing out and finding out, because there is so much as a new immigrant that you have to try and find out for yourself. This is another additional burden.

She acknowledged the support of Public Health programs and organizations like “Babies Best Start” in the GTA, which cater to children with disabilities, and their parents, from a wide variety of cultures, and stated, “it is improving.” Listening to mothers about what works is a clear indication that mothers, as experts in their field, need to be considered and given the opportunity to talk about their needs and how these can best be met. Increased funding could provide outreach support, which is one critical area that could help to identify marginalized mothers and provide them with increased opportunities for community social networking and supports.

All of these experiences outline some of the frustrations leading to a mother's overall lack of knowledge about where to go for help, which was another critical issue for one mother: “I felt a lot of emotions knowing that I could have harmed my son and nobody was listening to me.” For desperate mothers and parents, this pressure raises a number of questions regarding family and personal safety.

Ultimately, increased support for parents who might be suffering from compounding pressures might help to alleviate potentially harmful situations towards themselves or their children. Other issues not raised, but could be considered, relate to the potential for family violence in such high pressured situations. Immigrant women are not immune from family violence and although this was not a topic of discussion, it does raise some questions for further study; in particular, the way mothers, their children, and families can be supported under situations of duress.

Mothers cited some positive experiences with support service workers who were very helpful, insightful and “there at the right time.” Others encountered just the opposite and found their overall experiences to be constantly challenging. One mother stated that she felt “intimidated” by her contact with the social worker and expressed the need for the service workers to try to abandon preconceived notions by “com[ing] down to your level.” Another mother, struggling to come to terms with her son’s diagnosed medical condition, was at the time, shocked by the lack of interpreters at the hospital. Her experience, common to two other mothers for whom English was not their first language, was one of frustration. Her situation was exacerbated by the comments of the presiding doctor who, during the consultation, questioned the origin of her last name, which the doctor believed to be ‘atypically’ of Latin American origin:

They [the medical staff] were asking stupid questions like this Doctor said to me, like my husband’s name is [Family’s name withheld] and we were speaking Spanish? The Doctor asked me how come this last name is \_\_\_\_\_. I [couldn’t] explain why [or] how? It is from my husband...and his grandfather or great grandfather immigrated from Jamaica or England and went to El Salvador.

The mother later mentioned that after a number of years had passed, she had acquired enough English to read the report, which she stated, had been misinterpreted: “The doctor stated that I had told her that my husband was Jamaican and *there* it is in the report, which is *not* true.” This situation points to the need for increased interpreters and greater sensitivity extended to families at the time of diagnosis. Such a question, as described by the mother, also illustrates the influence and final result of how attitudes and individual biases, which are prone to misjudgment, can possibly influence medical records and other official documents. Historically, this was seen at the turn of the century when immigrants’ last names were subject to change based upon the subjective interpretation of the person recording the information at the time (‘O’Connor’ became ‘Connor,’ ‘Smythe’ might become ‘Smith.’) The present day example of the El Salvadoran mother demonstrates the subjective professional authority and privilege that professionals may exhibit in questioning a family’s personal details. This was illustrated by the doctor’s queries pertaining to

how this family could possibly have an anglicized last name. Even if the questioning is out of genuine curiosity, professionals need to be mindful of the timing and the type of questions that they ask the family, as well as the impact on the family itself. Moreover, how is this information recorded as an official medical record?

One mother received encouragement to participate in a conference on her child's disability (name and association withheld). An East Indian social worker recognized her situation as unique as an immigrant mother with a child with special needs, and consequently wished to promote her story: "I think that it would be a good experience for other Canadians to know about this family... as new immigrants... they don't speak English." The social worker believed that this family's situation needed to receive wide spread attention, which the mother reiterated: "Look at what we are going through. Yes, we are not white, we don't speak English, but we are having a hard time here. *Please* help us. *Nobody* listens... And they said No, and that was the first time I had that experience."

On representation within organizations, this mother would like to see greater numbers of immigrant families involved in some of the larger organizations, which would increase their visibility, but she does not feel that this was evident in her case:

Have you ever seen a Spanish family on a poster or any other family? I have seen Asians, but I have never seen black. I never seen Spanish. I never go into a conference where have been a Spanish speaking family at the front telling their stories, or other nationalities; it is not just Spanish speaking families. Every time I [have] been going, as a professional, as a parent, there is always a Caucasian person at the front telling their story, how they used [this intervention or that] ... [pause]... what about us? Have you ever think about us?

For this mother, being a "visible minority" and having a child with a disability has been a huge challenge for her in terms of inclusion, participation, and equitable support. Inspired by Terry Fox's story, this mother decided to come to Canada because of its tolerance for people with disabilities. However,

during her initial settlement, she felt disillusioned by Canadian attitudes towards disability which were contrary to her first impressions: “and I know that discrimination exists in here, but I was very naïve to think before that it didn’t happen here in Canada, but it does happen and it is well hidden-the discrimination against people with disabilities.” In addition, this mother felt:

There are more open doors for children who are not a minority-this has been my experience. There is more acceptance, more tolerance than for our children. Maybe it is because they are more assertive. I would like to see that this is a new generation for Canadians and [where] everybody has the same rights.

Her experience is supported by what Lopes and Thomas (2006) refer to as the “default to white” whereby institutional discrimination, defined as “the network of institutional structures, policies and practices that create advantages for white people and discrimination, oppression and disadvantage for racialized people” (p. 270) may be limiting the involvement and participation of immigrants. Such social exclusion may be inadvertently created by systemic racism characterized by the “conscious or unconscious policies, procedures and practices that exclude, marginalize and exploit racialized people which is supported by institutional power and by powerful and often unexamined ideas which make racism look normal and justified” (p. 270).

These ideas are also supported by Bell (2006) who believes that there is a tendency for individuals and organizations to “whitewash” (p. 275) issues related to disability, although a defensive position could be taken since no one appreciates being labeled racist, however, it is important to address “systems and ideologies which have shaped individuals and society by forcing them turn a blind eye toward addressing issues of systemic fairness” (Wildman & Davis, 2005, p. 97). These authors further add, that it is also the invisibility of privilege which strengthens the power it creates, and which is furthermore, sustained by silence (p. 95). This finding supports the comments of one the mothers who repeatedly reiterated how she felt that she was not “being heard.” She had something to say, yet was silenced, and dismissed on a number of occasions due to her accent and language limitations. She felt further silenced by being excluded from

participating in a conference proceedings when she felt that her story, as an immigrant mother with a child with a disability was neglected. She did not feel that it was given fair and equitable representation in organizations, which should fully cater to all individuals with disabilities and their families, regardless of race.

Lopes and Thomas (2006) illustrate that equity is a right, but that society often misunderstands the term since it tends to default to an understanding of gender and more recently to fair representation of differently abled-bodied persons. These are the only two variables, which can be considered from an institutional point of view (p. 146). They further note people of colour, or individuals from a visible minority are not often included in organizational structures because they may be viewed as bringing divisiveness to organizations (p. 146). This might be the case in some organizations, which need to address existing attitudes before change occurs. However, self-reflexive measures are only helpful if the results are acted upon.

In the GTA, settlement services such as settlement counseling, basic ESL classes including LINC classes and social work assistance are generally free of charge to immigrants. This is similar to the disability service sector, which provides free disability social worker intervention, advice, some educational assistance, and membership into disability organizations. Assistance from some larger organizations requires an annual fee contributing to administrative operations such as covering extensive websites, public education, literature, on-going communication, and research support. Although families in need are not turned away from such services, some families remain sensitive to their financial dependency and inability to pay and qualify for certain on-going educational incentives offered by organizations supporting young people with disabilities. One mother found these measures to be unaffordable and exclusionary. Though she would not have been turned down for services due to the inability to pay membership fees, she expressed that she did not want “to feel like a charity case” and be further stigmatized by her inability to pay. She believed that more families would be able to connect and feel accepted within such organizations, if fees were reduced or covered by the government:

So what happens if you are not a member of that society, or organization, you don't get a scholarship..." On not being turned away from services: "They will not turn you away from the services, that is true, but when you are there and you know you haven't paid, it doesn't feel right. It feels like you are the charity family, you know the welfare family, you are the one that doesn't fit in here and maybe they don't think that way, but you *feel* it that way.

Economic exclusion forces the stigma of exclusion to continue. One mother elaborates on the way she was treated by one organization:

The way they look at you. The way they treat other members they paid or donate[ed] money, it is not the same way that they are going to treat you. I had experience[s] with that because sometimes when I didn't have no money to go to a certain course, I have to say, "look I don't have no money", and then they will give me another treatment different than other parents [due to her inability to pay] and I *felt* it.

In the case of educational systems, five of the mothers felt frustrated with obtaining support and resources from mainstream schools when they needed it and stated that their personal lack of navigational knowledge was a major obstacle, as they "didn't know the system." However, due to a disparity of funding allocated to school boards in the GTA, cited earlier by Troper (2003), depending on the school board, on a number of occasions, the mothers were required to pay for assessments ranging up to or beyond a thousand dollars. As a result, two of the mothers incurred great expense and moved to other boards to obtain funding services, which they felt, should have been provided by the first board. These incidents raise questions about inequitable resource funding allocation across school boards; why this marginalizes those who can afford it from those who cannot, and why families have to move within the GTA in order to access the supports, which they need.

In terms of specialized services, two of the mothers of children with Autism received TPAS (Toronto Partnership for Autism Services) and IBI (Intensive Behavioural Intervention) funding for their

children. One of the mothers, in desperate need of intervention, wondered why she had never been told about this essential service. However, she hoped to find out more since her son was already four years old and did not want to miss the two-year funding allocation since funding in Ontario stops at the age of six. On a pessimistic note, the mother made a similar comparison to her experiences accessing respite care, adding that accessing this service is “ultimately [a question of ] getting in.” The other mothers of children who had already received two years of service felt that it was inadequate compared to Alberta. These inter-provincial funding inequities raise further questions about the mismatched priorities set by provinces. While Alberta may potentially have more money to support social services, regardless of expense, Ontario should follow suit, and not prioritize care if all individuals are treated equitably as citizens deserving of treatment to which they are entitled.

#### Future Concerns

Many of the mothers spoke about both their immediate and long-term future concerns as one large issue. The mothers’ immediate concerns pertained to the accessibility of services for their children such as early behaviour intervention measures (TPAS) for the children with Autism. One stated that, “the wait list is so long, I feel that they need to push more children out which is unfortunate.” Similar to Neufeld et al. (2002), the topic of waiting lists prevented mothers from acquiring the necessary services, which they needed. In addition, continuing day placements and programming for adults with intellectual difficulties after the age of twenty-one was another concern of the mothers in this paper. They added that meeting specific “established” criteria as well as enduring long waits for future living arrangements in independent live-in homes were other significant issues concerning the mothers when they were no longer able to take care of their adult children:

There are services, but you have to meet their criteria... [but] I’m not sure what their criteria is, but everybody’s got waiting lists....so many families are waiting for services. That is really, really, hard....and makes me angry...where money is being spent, [it] shouldn’t be it could be much better spent by giving these families the support that they need. And it’s not happening and parents

in the 70s still have their children at home. In many cases it is a single parent now because one parent has died...[long pause] And very little if any support and that...that's maddening [pause] because if there's a will it could be fixed, but I don't think the powers that be care, really.

Grassroots organizations in Canada (such as the Family Alliance) advocate against nursing home placements. In statements produced by Family Alliance (2006), representatives stated that families want choice in living arrangements provided to their children:

That's my biggest fear, dare I say the word [referring to her passing on]. I want to be here to see him grow up, go to high school, go to college, be a man. Heaven forbid if something happens to me. Who is going to look after my child? I feel like my family-they don't know how to take care of him. Will they be as patient? I have those thoughts sometimes [her son is age 6]. I shouldn't be thinking that way, but I do."

Four of the mothers expressed this long-term concern about what happens after the parent is deceased. All felt frustrated by the lack of opportunities and general consideration for individuals who have a child with a disability: "There's very little, if any support and that's [that's] maddening because if there's a will it could be fixed...[long pause]...but I don't think the powers that be care, really." She added:

I would like to see the families been given a choice and supported in their choices be it when the parents no longer can take care of them, be it other extended family, or people who will take care of them because they want to and they love them...and where they are treated with dignity and love.

Another parent brought up her concerns over "consideration for the age of the parents... [as] closing institutions with one brush was not a solution." She stated concerns over the lack of facilities created to accommodate the numbers who are leaving institutions: "some of them are on the street. They

[the government] closed them, but did not provide alternatives.” Combined with the growing number of older individuals with a disability, she raises a significant concern over accommodation:

Well, right now, they are putting them into seniors’ homes, which is not good. They are not seniors. They need the give and take of everyday life. Not the life that people in seniors’ homes lead... This seems to be the band-aid solution, right now, well, now we’ll put them in an old age home. Well, old age homes are for old people, not for people who are in their forties and fifties. That *has* to be addressed.

The concerns of the mothers all lead to future questions related to community care and how individuals with disability are accommodated into nursing homes. Furthermore, the needs of the elderly and older individuals with disabilities necessitate distinct service provision. Additional research is needed to address the implications of measures of placing individuals with a disability into long-term facilities, whether these accommodations are a short or long-term decision. As mentioned earlier, the push towards nursing home arrangements is problematic. *The Long-Term Care Access Protocol for Adults with a Disability* (2006) states that addressing the needs of individuals with disabilities as well as seniors is a right and consistent with “inclusive” communities. However, the push towards such containment and arguably, warehousing strategies as mentioned previously, gives both individuals and families little or no voice in directing their own living arrangements when it is being orchestrated by the government. This is a significant current issue affecting all families including new immigrant families and needs to be addressed.

#### Personal Factors

In order to understand how the mothers managed their many challenges, an essential interview question focused on how women managed to find the strength and resilience to keep going in the face of adversity. Although there is some overlap with other sections, the mothers’ resilience was an important area to mention. The findings are particularly relevant to service providers and health care professionals.

The use of the metaphor, “filling their pitcher” created by Baskin and Fancett (2006, p. 20), refers to the way in which many women in a constant giving role find ways replenishing their energy in order to continue functioning. I used the metaphor to help break up the pace and focus of the interview. Some mothers laughed at the fact that the question referred to them while others paused. All talked about their coping strategies. Four of the mothers noted themselves as the source of their own inspiration and another mother identified time alone as a source of comfort. Two of the mothers gave equal weight to their profession and friends as the key components to keeping their pitcher filled.

While the mothers may have had many, difficult moments acquiring services and assistance, there was no reference to “tragedy talk” which refers to their life situation as a tragedy; Brett (2002) indicates that this kind of talk, which is sometimes reinforced by the individual model of disability, also stresses parental disempowerment and dependency upon professional medical expertise (p. 829). On the contrary, the mothers felt inspired by their children “to do more” and focused on their children’s intelligence, and their tremendous capacity to care, and love. Their focus on their child’s abilities and not their disabilities helped the mothers to keep their pitcher filled, which was self-empowering. What should be noted is that service provision should not rely on this understanding of the mothers’ coping strategies, but rather should continue to provide additional ways to support them.

Seven of the eight mothers cited their religious beliefs as key to helping them cope. While some of them were able to attend faith related functions, others were not. One mother stated that she managed to watch the service on the television. All of the mothers had different experiences pertaining to their belief systems and their ability to exercise them formally or informally. One mother cited her inability to attend church because of her son’s behaviour, and other family pressures; however, she expressed sincere appreciation for others’ prayers and optimism for her situation: “It all helps.”

Support groups were another way in which women filled their pitcher. Five of the eight women cited such groups and regular contact with the other women as a key element in helping them cope since it was an important source of sharing knowledge and experiences. When meeting another mother who has a

child with Autism, it often took no more than a first meeting to arrive at a mutual understanding: “I feel that she understands me.” Being heard and understood were other essential components of the support group.

The mothers identified quite a number of stresses affecting their lives (as previously mentioned). However, the mothers were surprised when they were asked about the way in which their child “cared for them.” Reversing this last question caught the mothers off guard since they identified themselves as the primary caregivers providing for the majority of the child’s needs, not in reverse. Nevertheless, the mothers were delighted with the question and gave numerous examples of their child’s sustaining care: “he is a beautiful child [long pause and tears].” This mother spoke in awe of her child, but also talked about “his happiness...joy and attention.” One mother cited the importance of her child’s “hugs and kisses” as well as the “unconditional love” which her child provides.

Many affirmative emotions were expressed by the mothers as they shared, with excitement, the positive aspects of day-to-day parenting as well as the humour. One mother mentioned that her daughter “encourages me and gives me strength...Oh my goodness!...she cares for me a lot! And the *humour!* [laugh].” The mother adds that “my husband is quite an uptight person, but can never be uptight around her.” She acknowledges that her daughter is also a teacher. She reminds her mother and those around her of the importance of thankfulness and the smaller things in life: “she is so thankful of everything...and she remembers.” Other mothers mention the difficulties of parenting which seem to go unnoticed as questioned by one mother “Joy and happiness? Oh, gee...what is that? [laugh!].” She then adds, “just knowing, you know, that he’s here. He’s my son. He’s autistic, but *he’s* my son,” and “by him staring into my eyes...telling me he loves me, it gives me the strength... I tell myself that I have to be strong for him.”

Mothers found that their children were a tremendous source of inspiration and that in simple ways their children helped “care for them.” Their child and their child’s happiness was one of the significant factors providing them with the resilience to carry on despite the many tough situations that the mothers had encountered. Looking back over her years as a mother of a forty-three year old daughter with Autism, this mother stated that in order to manage day-to-day living, you have to develop “a tough skin.” Her faith

also helped her to accept her situation and manage it. She saw her daughter as a gift. “It’s just something that God gave you and you’re unique, because He knows that you can handle it [your child with a disability].” She stated that her daughter also knew that she was unconditionally loved especially “when this child hugs you and tells you that she loves you. It isn’t because she wants the car keys...you *know* she loves me.”

Many of the mothers appreciated participating in the research. They were very forthcoming with information and when asked, only three stated that they had been asked to talk about their story on previous occasions. One mother stated in relief: “I appreciate it because it [the story] hasn’t come out in a long time.” They each felt that it was important for her story to be heard, but felt underappreciated since people, (including some members of their families, did not even care enough to listen to the details; in many ways any discussion relating to their child’s situation was a conversation stopper. The women found this particularly upsetting. Their wish to be heard echoes in other studies which have looked at the power of not just story telling, but “telling” their stories which Williams, Labonte and O’Brien (2003) believe has the potential to uncover knowledge that has been subjugated by dominant ideas “particularly when groups are at the economic, or cultural margins” of society (p. 36).

It might be added that immigrant mothers of children with disabilities also find themselves located on what Dossa calls the “fault lines” of society; she stresses that society needs to address its reluctance to identify these systemic fault lines (Jetelina, 2007). Increased opportunities for mothers to speak about their experiences would help to uncover these fault lines and would increase societal awareness of their situation, which is the first step to implement change. As one mother clearly stated: “I want people to hear my story because I think that it is important to know what I went through, what my son went through, and what my family went through.” Finding ways to circulate this information would create greater awareness and understanding of their particular circumstances and would hopefully lead to their greater inclusion in community and service provision.

An important aspect of the interviews was to acknowledge the women's use of silence. Ross (2001), states that it is the listener's task to acknowledge silences marking particular kinds of wisdom and knowledge (as cited in Dossa, 2004, p. 116). Ross further adds, "women's silences can be recognized as language, and we need carefully to probe the cadences of silences, the gaps between fragile words, in order to hear what women say" (as cited in Dossa, 2004, p. 116). As a result, on many occasions, pauses were just as much a part of the interview as the words that were spoken. On other occasions, the mothers cried and laughed. Eye contact was also very important which helped me to remain as present as possible to the mothers' silent moments as well as to their words.

One mother described her feelings: "of course you feel bad. More than anything, you feel, you suffer...[pause]... more than anything, it's because of people's incomprehension and through this suffering, a mother, raising her child also suffers...[long pause]...it's like that." Her pause was long, emotional, and deep. Yet her tears could not be ignored, for her words were very real to her situation, driving her to seek a better life for her adult child in Canada, a country that she believed to be understanding and tolerant of individuals who have a disability.

Women's silence is also indicative of the need to provide women with participatory opportunities so that women can voice their concerns and take a more active role in informing program designs and in determining services for their child. This idea is supported by Finkelstein (1998) who believes that individuals, (and in this case mothers) need to be able to contribute to the formulation of the service system where they can both advise and communicate their needs which in turn, will give them the support that they need (p. 13). Time and resources need to be allocated towards acknowledging the mothers' knowledge and experiences despite cutbacks and continuing "care deficits" (Arat-Koc, 2006b, p.1). Evidenced based policies would then reflect the goals of social inclusion as defined earlier by Omidvar and Richmond (2003) and help women both individually and collectively locate the services which they need for their child during the stages of initial settlement and throughout the long-term.

## V BENEFITS OF THE STUDY

It is my hope that the recommendations coming from this paper will be a helpful resource for settlement service providers, disability service providers, school boards, and government policy makers. An awareness of the difficulties encountered by mothers would help to inform program funding allocations, policy design and adaptation. A shift in perception regarding the needs of mothers and their children would increase societal awareness, respect, and grant mothers the resources to which they are entitled.

As immigration and consequential settlement needs increase in the GTA, both the settlement and disability service sector would benefit by developing and incorporating a deeper recognition and understanding of the complexities of disability issues. In doing so, service agencies could connect with families at vital points in the child's life as well as during the period of family settlement. Policy makers could direct funding toward the education, training of settlement and disability support councilors, and social workers concerning the types of services, supports, and resources available in the GTA. Families would therefore be matched with services without unnecessary waits.

The number of immigrants and newcomers receiving disability supports in the GTA is an important topic that has not been widely documented in academic research. Immigration, settlement, and disability issues are relevant today and merit further study, particularly with an increase in miracle babies, environmentally related accidents, and conditions as well as the increasing numbers of baby boomers who are developing age related disabilities. An understanding of disability needs to be more widely appreciated and understood as a condition, which may not just be acquired biologically, but acquired at some point in a child's life and by extension, at any point in an adult's life too. It is merely a question of time and is cause for concern particularly if the concept of temporary-'able-bodiedness' is embraced and considered in its greater context as affecting both children and adults. In discussing the needs of the mothers of children with disabilities, it is in supporting the various types of organizations within the disability and settlement services sector as well as in schools, and specialized programming that individuals, their mothers, and families will get the support and attention that they need.

## VI LIMITATIONS OF THE STUDY

The study was exploratory in nature since it was anticipated that recruiting mothers might be difficult. Consequently, a number of mothers of both first and second-generation were interviewed, including a recent mother who was claiming refugee status in Canada. Her limited time in Canada did not detract from the research but rather provided rich experiences, which were in some instances similar to the other mothers in the interview. Future research directions could include studying the situation of refugee mothers who have lived in Canada for at least a year. However, recruiting refugee mothers for interviews could be difficult given that one's immigration status is a delicate and confidential topic. Participants might not come forward for political and personal reasons.

Other limitations included a varying sample of participants in that some mothers had young children while others were already young or older adults. This created varied lifetime lines in the study and affected acculturation patterns, which were uniquely experienced by both first and second-generation mothers at various points in their lives. However all of the mothers' life stages provided rich data for the purposes of illustrating the types of social exclusion, which they had encountered, however different were their experiences.

Due to the prevalence of issues which the mothers were facing as well as the variety of time frames of experience and types of disabilities which their children had (some mothers had very young children, others had adult children), the use of retrospective data was perhaps at times down played according to the prevalence of issues in the mothers' lives. The emotional responses of some mothers may not have been as high or as responsive as if they were still deeply involved in caregiving issues affecting for example, school and integration, or initial settlement experiences. Similar to what Pelchat, Lefebvre and Perreault (2003) experienced in their study, mothers may also have censored their own comments about their present or past experiences, which they were entitled to do since all information was relayed voluntarily. This experience however, simply notes another interview dynamic, which occurred and may have limited some information. Overall, some mothers talked about their experiences in the past, but also strongly stated their present concerns, which were more relevant to their situation.

Three of the eight mothers experienced specific racialized incidents. However, some of the women may not have delved into much depth since issues relating to racism may have had the potential of calling up other emotions. My position as a white, female researcher also may have caused them to be reserved about certain elements to which they were entitled since all information was voluntary.

Children were not used in the study, due to research ethics review, but one aspect that could be further addressed is the way, for example, immigrant children with disabilities such as Autism (or Autism Spectrum Disorder) experience their disability and negotiate belonging in the GTA. What are their relationships with family, school, friends, and society? Ethnographic examinations of mothers and even young adults could uncover additional insights concerning cultural perceptions. Longitudinal studies could examine the long-term effects of settlement and the way these types of experiences affect the lives of women in the GTA particularly from an immigration policy point of view.

## VII KEY RECOMMENDATIONS

The following key recommendations are based on the findings, the mothers' suggestions and how their repeating concerns influence their daily lives. The findings call to question policies and social service funding allocation, and how these can be changed as well as redirected to ensure that immigrants and their families thrive by helping them to access the supports they need personally, educationally and socio-economically. It is the due diligence of the government to look at the social concerns, address and implement change, and look after its citizens, which is reinforced by Burstein & Duncan (2003). Since relatively little information exists on the topic of settlement and disability in the GTA, the following recommendations, based on social inclusion framework of Omidvar and Richmond (2003), will address policy makers, social service providers, and academia. As immigration numbers increase in Canada, I hope these suggestions will help to address some of the disparities, which exist in policy, and service provision in Canada, Ontario, and in particular, in the GTA.

## Settlement and Disability Service Sectors

1. Allocate increased funding to settlement services to assist families who may have a family member with a disability. This could help to advance their overall settlement
2. Increase the number of social workers from varied ethno-specific backgrounds, provide cultural sensitivity training, and increase bridging opportunities between the two fields.
3. Reduce or eliminate membership fees services or provide subsidies.
4. Increase informal gatherings and opportunities for parent and mothers' support groups.
5. Consider the impact of cultural brokering on siblings of immigrant families with a child with a disability, particularly if the parent should fall suddenly ill, or acquire a disability.
6. Encourage informal networks of support to create faith-based outreach services for mothers and parents who may in fact be classified as "shut-ins" and are isolated from formalized congregational activities (if the child's behaviour may not permit regular visits).
7. Create informal literature and media information in a number of languages informing a wider variety of parents, mothers service providers and the public about settlement, and in particular, disability services that are available to parents in the GTA.

## Educational Supports and Services

1. Increase resources to improve the facilitation of a child's transition from specialized programs into mainstream schools.
2. Create schools that are more inclusive. Integrate disability studies into the curriculum from Kindergarten to Grade 12. Disability awareness should not exist in isolation, but in relation to everybody.
3. Increase early intervention programming and workshops for parents, educators, and social service providers so that suspected issues can be identified, the necessary supports put into place for the child. These measures would also compliment an increased number of Occupational and Speech Therapy, Language Pathologists and Special Education provided to school boards.

4. Create and support theoretical and practical professional development for new and existing teachers highlighting recent data pertaining to immigration, settlement, and disability studies.
5. Increase professional development training for issues related to cultural competency and equity as it pertains not only to gender, but also to other factors such as race, culture, and socio-economics. A greater awareness and more holistic understanding of the settlement needs of families with children with special needs, newcomer children availing of ESL, or second-generation immigrant children for whom English is not the language spoken in the home. The above points could be developed, implemented by the Ministry of Education and by school boards, and incorporated into professional development for teachers in all courses, and at all stages of their career.

#### Financial Supports and Services

1. Increase funding for essential respite services for parents to reduce long waits and provide caregivers with necessary breaks to continue caring for their child.
2. Increase specialized funding of programming for children with Autism and create early intervention strategies and programming to ensure that children are not overlooked or missed due to extensive waiting periods.
3. Provide increased individualized funding initiatives which would give individuals and families choice in their child's future educational and long-term life plans.
4. Increase the availability of resources and support services: increase the number of special education specialists (OT's and Speech Pathologists) to increase early identification and intervention; increase adaptive devices, teaching resources, and Educational Assistants to facilitate in-classroom support to teachers with multi leveled student needs.
5. Provide equitable resource funding to all GTA school boards for assessments and resources to prevent parents from having to move to boards in order to obtain the supports that they need.
6. Increase funding for day programs, post-secondary educational opportunities including vocational programming, and university settings.

## Government Recommendations and Program Transparency

1. Fill knowledge gaps so parents will be aware of services and funding which is available for their child's needs. Fund bridging programs to connect parents with these services.
2. Increase badly needed group and independent living options so as to reverse the trend from de-institutionalization to 're-institutionalization,' to community-based housing opportunities for adults.
3. Recognize the importance of funding increased interpretive support services for parents.
4. Ensure that social and settlement workers are aware of current programming, subsidies, and opportunities for mothers and parents. As culture brokers, social workers are also essential mediators between source information and the mothers.
5. Implement public and private sector recognition and employment caregiving policies such as job flexibility, increased day care as a public priority, increased respite, and long-term respite options for adult children of aging immigrant mothers. Also recognize the private caregiving demands on women and the increasingly complex multiple roles that parents have in caring for their child with special needs as well as providing caregiving support to an aging parent, either here, or overseas. A life-cycle approach as outlined earlier by Omidvar and Richmond (2003) would thereby consider more holistically caregiving, at all stages and circumstances of a mother's life.

## VIII LOOKING FORWARD

Looking towards the future, comprehensive needs assessments created by the government or service providers could determine the numbers of individuals with disabilities in the province and GTA and the types of services that they use, or under use. Such assessments could also determine which immigrants with disability-related issues are being missed and why? Other research studies could focus on the longitudinal aspects of understanding immigration, settlement, and disability issues. Service providers and other professionals could be surveyed, or interviewed to determine their personal and professional concerns, and need for support. What do they feel are significant service delivery issues and obstacles, which they face? Do they feel that they are able to provide adequate services to newcomers? What are their recommendations? The results of such a study would be helpful in addressing perceptions, and in creating bridging programs between various health, settlement, and disability-related social services.

Canada faces challenges in continuing to secure educational opportunities for children regardless of their age and ability. This specifically refers to specialized autism services for young children such as IBI (Intensive Behavioural Intervention) which should not discriminate against age, and should become a priority need in Ontario. Additional programs could be created to address educational day programming for individuals with an intellectual disability as well as increased post-secondary educational opportunities and funding for young adults in high school and beyond.

In addition, future research could investigate the roles and responsibilities of extended kinship support in the source country and here in Canada. How do immigrant families caring for a child with a disability manage overseas caregiving such as remittance support and caregiving to parents and family abroad? What is the socio-economic and psychological impact of such caregiving provision on their families here? Various family members could be interviewed to develop an understanding of the types of intergenerational support that families receive or provide.

Although one would like to think that one is immune, issues of aging and or disabilities are a reality, which implicates all individuals. With the rising numbers of Canadians retiring and in need of specialized care, health care, and service policies need to address, the specific and multi-dimensional needs of senior immigrant women. Mothers might find themselves alone as primary caregivers to their adult child, or even grandchildren in the family should an illness, a spousal death, divorce or separation occur. They also need to consider the complexities of providing full-time care to their adult children with a disability. What are the other long-term housing options provisions for families? Are nursing homes, or long-term care homes the only present option. Ministry initiatives need to find ways to accommodate the needs of all family's promote their inclusion and deliver the concrete support, which they need.

As Robert Harney (1940), Toronto's pioneering scholar of immigration stated: "No great North American city can be understood without being studied as a city of immigrants, of newcomers and their children as a destination of myriad group and individual migration projects" (Siemiatycki et al., 2003, p. 452). As a leading country of destination, Canada's future progress depends on research and service development aimed at providing for, and including all of its citizens in programs and policies. No one should be forgotten, particularly those individuals and families most marginalized, and needing support.

## IX CONCLUSION

The qualitative nature of this research represents the lived experiences of mothers, including the multi-faceted settlement experiences, as demonstrated by immigrant mothers of children with disabilities. It demonstrates that throughout the various stages of settlement, mothers, on whom the majority of caregiving falls, still experience much difficulty in accessing the supports that they need from services, (family and ethno-specific supports) regardless of when they arrived. One difficulty is that while some families have larger immediate families, which are the centre of their supports, other mothers were on their own. The single mothers without supports lived on a fixed income and cared for their child single-handedly. As identified earlier, they are often the most marginalized and isolated from family and mainstream community supports.

This paper highlights gaps in literature pertaining to barriers to inclusion faced by mothers as related to gender, race and by extension, their child's disability as well as the way in which the combination of these three elements impact the mother's lives. As caregivers, mothers have developed an expertise about disability: they have first hand knowledge about the needs and realities of both their children's lives and that of their families. Their staunch fight for their children's rights needs to be acknowledged. Gaps in the literature can also be addressed if efforts are made to make the mothers' stories visible so that they are publicly recognized in a variety of formats.

By implementing a social inclusion framework as outlined earlier, settlement, disability, and other mainstream organizations can examine more closely and make visible the ways in which their power, as a creator of privilege, is used to promote a more equal and inclusive society. Increased settlement support, an understanding of the issues, guidance and direction from community, and social service providers, will all help to ease the transitional gaps, the exclusion, and will also provide ongoing settlement support for mothers, particularly single mothers. Such support will prevent the mother's continued social isolation and marginalization from becoming worse, and would re-emphasize the importance of inclusive, and more transparent provincial, and local policies identifying, reaching out to help vulnerable families. This would help to close the physical, social and, economical distances which Li (2003) describes, and provide a "more enlightened view of integration and how Canada reaches out and truly supports all of its newcomers" (p. 12). Li further acknowledges that immigrants "offer unique perspectives to be appreciated as assets in the building of a global and diverse society" (p. 2).

Gentle warriors in their own right, mothers must be granted increased recognition of their human capital; that is, their knowledge, skills, resilience, and hope. As one mother stated, mothers have to have tough skin to endure many challenges, but this should not be a reason to overlook the day-to-day vicissitudes, and social exclusion, which these mothers face. I had the privilege of being present to the mothers' words, their tears, and joys, which provided a mere, but privileged glimpse of their lives, both past and present. The final words of one mother summed up her dreams for the future as she hoped for

“more awareness of not just Autism [in her case], but of all people disabilities... and what their families have to cope with. Greater awareness will make it a better world for everyone.” Echoing this mother’s sentiments, it is also my hope that the findings in this research paper will contribute to change: the creation of increased social service funding initiatives supporting both settlement and disability service sectors. It is also hoped that these research efforts will be transformative of societal attitudes, and contribute to the building of a more inclusive society; one that is more accepting of immigrants who face disability-related issues.

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APPENDICES

Appendix A

*Recruitment Flyer*

**YOUR VOICE COUNTS!**

- Do you have a child with a developmental disability?
- Are you a recent newcomer to Canada (as an immigrant or refugee?)

**Tired, Stressed, Frustrated?**

**Your insights and first hand experiences are valuable!**

**Mothers are invited to participate in a friendly, informal, and confidential interview that will help to increase awareness regarding their experiences parenting a child with a disability in Toronto and the Greater Toronto Area (GTA).**

As a gesture, [a token of appreciation, \\$20.00, and refreshments](#) will be provided for your time, insight, generous participation, and feedback.

For further information, please contact Majella at [mskrinda@ryerson.ca](mailto:mskrinda@ryerson.ca) or at **(416) 972-7635**

All interviews will be conducted in [English, French, or Spanish.](#)

Note: Services that mothers receive will not be improved as a result of participation in this research project. However, it is hoped that participation in this research will provide valuable insights, which may help to shape future changes in policies and services. Thank you for your time and consideration.

Knowledge of participant participation or non-participation in this research study will remain confidential: It will not be known to others including service providers.

[This project has received ethics approval at Ryerson University](#)

Appendix B

*Recruitment Letter*

Dear \_\_\_\_\_,

September 4, 2007

My name is Majella Skrinda and I am a graduate student in the MA program of Immigration and Settlement Studies at Ryerson University, here in Toronto.

I am very much interested in conducting research regarding the experiences of immigrant women parenting children with disabilities. I would be open to meeting mothers who would be willing to meet with me for a one-on-one paid interview about the challenges, which they face. I can travel to meet them at a convenient location.

I would very much appreciate your efforts in circulating my research interests by posting a recruitment poster in your office, on your web page or by passing it along to other employees or interested parties. I would appreciate a quick note in response to this letter to verify that this is a possibility.

Should you have any queries, I would be most happy to discuss them with you. I can be contacted by e-mail at [mskrinda@ryerson.ca](mailto:mskrinda@ryerson.ca) or at (416) 972 - 7635.

Thank you so very much for your attention regarding my request and I look forward to your response.

Yours sincerely,

Majella Skrinda  
MA Candidate  
Immigration and Settlement Studies,  
Ryerson University

## Appendix C

### *Interview Questions*

- 1) Tell me about your experiences parenting a child with a disability.
- 2) What has been the biggest challenge for you in caring for your child? (possible probes: care, behaviour, housing, accessibility to services, education)
- 3) What helps you cope? (possible probes: connecting with family, friends, neighbours, faith, personal time alone)
- 4) Where do you find your strength and how do you “fill your pitcher”, refill it or keep it filled? (possible probes: family, friends, neighbours, faith community)
- 5) How does your child support, care for you?
- 6) What other caregiving roles do you have? (possible probes: parents, kin, extended family)
- 7) What kinds of supports are most helpful? (possible probes: family, neighbours, community services, friends, faith community)
- 8) What role does your specific ethnic-community play in your life as you parent a child with a disability? (possible probes: advice, assistance/help and in what way? support groups and types, other community events)
- 9) What kinds of services are you able to use in the greater community? (possible probes: day services, respite- break for caregivers; nursing- medical care, home visits, organizations in the community, transport)
- 10) What suggestions would you have for the government to improve the situation and that of other parents? (probe: community providers)

